

SWINE FLU AND ME/CFS - QUESTIONS AND ANSWERS (version 2)

The ME Association is receiving a wide variety of questions about swine flu (swine flu virus H1N1) and how the pandemic might affect people with ME/CFS.

The numbers affected in the UK are now rising quite quickly – the current official figure is around 55,000 with 29 deaths but the true total figure is significantly higher.

The situation regarding management is constantly changing - so this is our current advice and information on the most common questions we are receiving.

We will be updating this website posting at regular intervals to take into account the latest official medical advice from the Dept of Health and feedback received from people with ME/CFS.

Version 2 contains information on children; how to try and differentiate between ME/CFS symptoms and swine flu; and more information about Tamiflu.

1 Are people with ME/CFS more at risk of catching swine flu?

Overall, the answer is probably no. However, if you belong to a sub-group who easily pick up infections, especially coughs, colds and flu-like infections, then the risk of catching swine flu may well be slightly higher than for normal healthy people.

2 Can children and adolescents catch swine flu?

Yes, and the symptom pattern appears to be very similar to that seen in adults (see question 7). There are now a few serious cases involving a small minority of children – whose immune systems obviously have no natural resistance to this infection. Consequently, the use of antiviral medication (Tamiflu) will need to be considered in this age group. Infected children should obviously remain off school but the Dept of Health is not normally recommending the closure of schools where cases exist.

3 How can I avoid catching swine flu?

In very simple terms, the more people you come in contact with the higher the risk - especially people who are coughing or sneezing! The highly contagious time for people who have the virus is around the time when they have first have symptoms. So try to keep away from crowded public areas and public transport, including aeroplanes - if it's not really necessary. This is particularly important if you have an 'at risk' illness (see point 6) as well. Simple avoidance measures and hand washing will help to reduce the risk but you cannot eliminate it completely. Coughing and sneezing also spreads viral droplets onto hard surfaces such as door handles, keyboards and phones - where they can remain infective for up to 24 hours. This is another important form of transmission. Wearing a cheap face mask isn't thought to be a very effective form of protection!

4 How dangerous is swine flu?

At present, the virus appears to be of similar virulence to any other type of flu virus - but it may be causing more severe respiratory symptoms in some people. So the vast majority of people are experiencing a relatively mild illness. If the virus starts to mutate (ie swap or change its genetic make up) and different strains emerge then the situation could become more serious quite quickly. As with any other flu like virus, there are going to be occasional cases where perfectly healthy people develop severe complications (such as pneumonia). People with 'at risk illnesses' - such as asthma or cancer - will be more likely to develop potentially serious complications. This is the reality of any infectious disease.

5 Are people with ME/CFS more at risk of developing complications from swine flu?

Overall, there is no evidence to indicate that people with ME/CFS are more at risk from developing complications that can occur with swine flu. However, those who are more severely affected, especially anyone who is bed-bound or prone to chest infections, may be more at risk from respiratory complications. And as many people with ME/CFS experience a relapse or exacerbation in symptoms whenever they catch a viral infection, an episode of swine flu may well make your ME/CFS worse.

6 Does it make any difference if you have other medical conditions?

Yes, it can make a significant difference. Because swine flu is an infection that affects the respiratory tract/lungs, those with any form of respiratory disease - asthma, chronic bronchitis and COPD in particular - are more at risk from developing potentially serious respiratory complications. And if you already have a chronic lung disease it's important to make sure that you are controlling symptoms with medication as well as possible.

Other illnesses that increase the likelihood of serious complications include:

- diabetes
- liver and kidney disease
- chronic neurological disease that affects respiratory function
- heart disease
- immune system deficiency caused by cancer, leukaemia, and drugs such as steroids
- pregnancy, - especially during the third trimester - where the immune system is naturally suppressed
- young children under 5
- the over 65s - although people over the age of 60 may have some partial immunity to the virus)

Although a variety of immune system abnormalities can occur in ME/CFS, these are not usually consistent with the sort of immune system deficiency that makes people much more susceptible to this type of infection.

7 What are the main symptoms of swine flu?

At present, swine flu tends to present with an acute onset of some or all of these typical flu like symptoms:

- a sudden onset of fever - 38 degrees c or over (but not always present)
- cough (can be dry) or shortness of breath
- headache
- sore throat
- sneezing and/or runny nose
- aching muscles
- loss of appetite
- diarrhoea

But this picture may change if the virus mutates and new strains emerge.

You can do a very helpful symptom check on www.nhs.uk.

8 How can you tell the difference between ME/CFS flu-like symptoms and swine flu?

This may not always be easy as some of the symptoms clearly overlap. But swine flu should always be considered where there is a new or sudden onset of flu-like symptoms - especially if this includes sneezing and cold-like symptoms, respiratory symptoms or a cough, and a definite fever. The key advice here is to trust your instinct - if something different with flu-like symptoms is clearly happening seek medical advice as soon as possible.

9 Where else can I find the latest information on swine flu?

- call the Swine Flu Information Line on 0800 1 513 513
- websites: www.direct.gov.uk/swineflu and www.nhs.uk

10 What should I do if I have new flu-like symptoms that do not seem like ME/CFS?

For the vast majority of people an episode of swine flu will not be that all that different from any other type of flu. This can be normally treated at home with rest, plenty of fluids and painkillers (paracetamol or ibuprofen). Swine flu symptoms tend to last for no more than a week.

If you are concerned about the severity of symptoms - especially chest symptoms or drowsiness - you can obtain more advice by:

- calling your GP - who may be able to give a diagnosis over the phone rather than you visiting the surgery. This is because visits to a surgery by people with the infection will help to spread the infection to vulnerable people in the waiting rooms who have illnesses such as cancer
- calling NHS Direct on 0845 4647 (England)
- calling NHS 24 on 08454 24 24 24 (Scotland)
- calling NHS Direct Wales on 0845 4647
- calling 0800 0514 142 (in Northern Ireland)

The Department of Health are setting up a specific National Pandemic Flu Service helpline and website that can give diagnostic advice and take some of the pressure off GPs. This should be up and running by the end of this week. More details in our

next update.

If symptoms are serious or deteriorating, and you are unable to obtain advice from the above, you should phone the accident and emergency department at your local hospital.

11 What are Tamiflu and Relenza?

Tamiflu (oseltamivir) is an effective antiviral drug that works by reducing the replication of the virus. Tamiflu will :

- relieve symptoms
- slightly shorten the duration of symptoms and infectivity
- reduce the chances of serious complications such as pneumonia

If you have an illness such as asthma that puts you at increased risk of developing complications from swine flu it's important to start taking Tamiflu as soon as possible. To be effective the drug really needs to be used within 48 hours of the onset of symptoms. Antiviral drugs are being given out by doctors in relation to individual circumstances - they are not necessary in every case. And they are not normally being given as a prophylactic/preventative measure to contacts of cases - unless there are special circumstances.

Tamiflu side-effects can include nausea, which appears to be the most common, and can be reduced by taking the drug with or immediately after food, and drinking some water. Other possible side-effects include vomiting, abdominal pain, dyspepsia, diarrhoea, headache, fatigue, insomnia, dizziness, conjunctivitis, epistaxis (nose bleed) and a rash. Very rare but more serious side-effects include hepatitis, Stevens-Johnson syndrome, toxic epidermal necrolysis and neuropsychiatric disorders. The drug should not be taken by people with kidney disease and not normally during pregnancy (where safety remains uncertain). It can be given to children. At present, we only have one report from someone with ME/CFS who has taken Tamiflu - there were no problems here.

Relenza (zanamivir) is another antiviral drug. This drug is inhaled and is suitable for use in pregnancy. However, it can cause bronchospasm (airways spasm), urticaria and skin rashes. It needs to be used with caution in anyone with asthma and lung disease.

12 Should people with ME/CFS take Tamiflu?

The simple answer at present is probably yes - but this is clearly a decision that has to be made in relation to individual circumstances. Tamiflu appears to be a generally safe and effective treatment with a low level of side-effects. So it is a drug that should be seriously considered when a person with ME/CFS develops swine flu, or has symptoms suggestive of swine flu - the main reason for use being that the swine flu infection could well cause an exacerbation of ME/CFS.

13 How do I get Tamiflu?

You currently need to be diagnosed by a doctor/GP.

But we understand that the DoH national flu line will shortly be offering a diagnostic service and a website is also being set up to offer computerised diagnosis. A member of staff will issue you with a reference number. This is then taken – preferably by someone healthy – to a pharmacy, or other collection centre, where the drug will be dispensed.

14 When will a swine flu vaccine be available?

Now that the genetic make-up of the virus has been identified, scientists are rapidly developing a vaccine that will be based on a killed virus. The latest information we have is that this new vaccine (two doses will be required) may be available from September or October onwards once it is licensed for use - probably without all the normal very strict pre-marketing checks for safety. Once the vaccine is ready for use, and we know more about it, we will issue further information in relation to its use in people with ME/CFS. This will take account of the fact that ordinary flu vaccine can sometimes cause an exacerbation or relapse of ME/CFS symptoms. At the start of mass vaccination, top priority will obviously be given to people with 'at risk' health conditions.

15 What is the situation regarding foreign travel?

If you are planning to travel abroad, check with the Foreign and Commonwealth Office travel advice at: www.fco.gov.uk/travel or call 0845 850 2829 and don't travel abroad if you have symptoms suggestive of swine flu. Make sure your travel insurance is up to date and you have an European Health Insurance Card (what used to be an E111). If you cancel a trip due to swine flu, you should be covered by your travel insurance policy - although some policies do have an exclusion clause relating to pandemics. If you cancel because you are worried about swine flu, it's unlikely that you will be covered for any financial losses.

It's worth noting that the UK is regarded as a high risk zone for swine flu and there is talk of some countries introducing thermal scanning at airports. This could mean that people travelling with a fever or other flu like symptoms could find themselves being refused entry on arrival.

Most European countries have health facilities that are up to date with swine flu management and Tamiflu may/should be available - if required. But you do need to consider what would happen if you intending to travel to a country with less good health facilities. Your GP may be willing to prescribe Tamiflu on a 'just in case' basis if you want to take some with you.

PREPARING FOR SWINE FLU

The Dept of Health recommends that everyone should have a network of 'flu friends' in place who could help out if you fall ill. This is obviously going to be far more important if you live alone or are housebound.

We hope you find this information helpful and practical.

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