

the only charity concerned specifically with the needs of those who have Severe ME

https://25megroup.org/me

## re Coronavirus and members of the 25% ME Group, Severe ME charity

Message from Dr Nigel Speight, Medical Advisor to 25% ME Group https://25megroup.org/patrons-trustees-advisers

I have been asked to give some medical advice on the subject. I should stress that I have no real expertise on epidemics like this.

However, one can say the following on common sense grounds:

It would seem very possible that the disease will spread throughout the UK and cause a real epidemic

Therefore anyone and everyone will be at risk of catching it before the epidemic burns itself out

There is no vaccine currently available

It is possible that some antiviral drugs might help a bit

Clinically it sounds like a nasty flu-like illness with a special liking for causing viral pneumonia

One can catch it from people who seem pretty well, in the early stage of their illness

Currently the mortality rate is thought to be c 2%, and "people with chronic conditions" are at especial risk

Although ME is a "chronic condition" my gut feeling is that they are not actually at greater risk of dying from the virus itself than healthy people. The conditions which put people at extra risk would be things like severe asthma or COPD, or immunosuppressed people eg those on chemotherapy for cancer

The biggest worry therefore for ME sufferers is that catching the virus will make their ME much worse, and of course people in the 25% group do not have much leeway. It might even be that worsening of their already severe ME could be a bigger threat to life than the virus itself

So what advice follows from all this?

I would think that the most important aim is to avoid catching the virus in the first place, and to survive until the epidemic passes. Of course, 25% members are actually at lower risk of catching the virus because they hardly go out at all!

However. I would advise you all to be as fussy/paranoid as possible about not coming into contact with visitors or health workers who might be infective. Don't feel guilty about being labelled "over-anxious", this is really important. Consider discouraging as many visitors as possible for the time being if you can tolerate the isolation

Anyone with cold/flu like symptoms should not visit anyone in the 25% group. ,This could be awkward if a carer is involved. Additional Vit D ie 2000 units cholecalciferol daily would be helpful for both patients and carers in order to fortify the immune system against the virus.

Good luck Dr Nigel Speight

(Dr. Willy Weir also contributed to Dr Nigel Speight's advice)

\*\*\* This is not intended to be a substitute for individual professional medical advice, diagnosis, or treatment. Always seek the advice of your own physician or other qualified health provider with any questions you may have regarding your medical conditions. It is not the policy of the charity, as alone we are not qualified to give medical advice. Please check your own country's health service advice and government guidelines

For UK members:

NHS advice

https://www.nhs.uk/conditions/coronavirus-covid-19/

Government information

https://www.gov.uk/guidance/coronavirus-covid-19-information-for-the-public

Overseas members should check the advice/guidelines fro their own country's health service and government

25% ME Group website https://25megroup.org/memberships

25% Severe ME News Group Facebook page https://www.facebook.com/groups/1421378731464024/