

Coronavirus (Covid-19): Frequently asked questions

Are people with AT more at risk from Coronavirus than the general public, if they get it?

There is a lot that we don't know for certain about the Coronavirus. There is as yet little certainty about the level of risk to children and there is certainly no data on people with AT. At the moment we are not aware of anyone with AT having been diagnosed with the virus.

The other thing to say is that AT is a variable condition. Some people have immunodeficiency, though this varies from person to person, others don't. Some have problems with their lungs, or diabetes, others not. It is very probable that there is not a single level of risk for all people with the condition.

Nevertheless, it is highly likely that some children and adults with AT who contract the Coronavirus are at greater risk of more serious complications than the general population. This is particularly the case for those with classic AT and where the person with AT has lung problems, is prone to infections, has known immunodeficiency, has diabetes or is under treatment for cancer.

For this reason, we strongly urge everyone with AT and those around them to do everything they can to avoid contracting the virus, and if they do to seek medical advice quickly, making sure you mention AT.

What steps should we take to keep someone with AT free from the virus?

The Government has now identified a group of around 1.5 million people, including children, that they consider "are at very high risk of severe illness from coronavirus (COVID-19) because of an underlying health condition". The Government says that people in this group will be contacted individually by 29 March.

While this has not yet been formally confirmed, it is the AT Society's understanding that people with AT are included in this group. In confirmation of this we know of at least one parent of an AT child who has received an email from the NHS Coronavirus Service saying that they "have identified that you're someone at risk of severe illness if you catch Coronavirus".

For this group, the NHS is recommending what they call 'shielding'. This is in their words a "practice used to protect extremely vulnerable people from coming into contact with coronavirus. What is involved in this is set out in detail by Public Health England on their website here <https://bit.ly/Covid19Shielding>. If for any reason you are unable to access this link for information, please do feel free to contact us.

Whether or not you receive a letter, and remember that this could be at any time up to the 29 March, **the A-T Society strongly advises people with AT and their families to follow the guidance set out in this link.**

The guidance seems mainly written with non-disabled adults in mind. Where children with AT or significantly disabled adults are involved, it will probably be impractical to ensure the reduced levels of contact suggested by the guidance. In this case it may be advisable that one or more carers undertake the shielding with the person with AT and that the distances are kept by both from other family members. This is particularly the case where people are continuing to leave the house and have contact with others, eg for work.

While it is hard to generalise or give advice for every situation, broadly the AT Society recommends that you use your common sense and creativity to adapt these principles to your own circumstances. The key principle is to **protect your household from potential contact with the virus to the highest degree you can.**

If you have concerns about anything, e.g. how this might impact on employment or other aspects of your life, please feel free to contact us.

Children and schools

Prior to the closure of schools, many families had already taken the decision to keep children with AT and any siblings away from school. This was clearly an understandable step in keeping children from contracting the virus.

We do not envisage that there will be any negative come-back to families that did this, but to be clear, the AT Society will support families that made this choice. The AT Society produced a statement of support for families in these circumstances, which you can find in the guidance on our website. If you need a copy of this, or a more personalised letter, please contact us at support@atsociety.org.uk or on 01582 760733.

Employment issues

If you have any issues with your employers resulting from AT, for example around having to take time off work as a result of the need to shield a family member, or anything else, please do contact us for support either by email at support@atsociety.org.uk or by phone on 01582 760733.

What should we do if someone with AT or a member of the household develops symptoms of the virus?

The advice from Public Health England is that if anyone with a condition like AT develops symptoms of the virus (high temperature and/or new and continuous cough) then they and all members of the household should isolate themselves for 14 days. More advice can be found here bit.ly/Covid19Stayathome.

While the advice for the general public is that there is no need to contact NHS 111 or your GP if symptoms of the virus are found, (unless these start to get worse), **if a child or adult**

with AT becomes ill, you should seek medical care promptly. At the present time, this has to be through NHS 111. Make sure that you inform them that the person has AT.

We would ask you to let the AT Society know if a child or adult with A-T has a suspected or confirmed case of Coronavirus. This will enable us to help ensure that you have all the support you need, but as importantly, by gathering information on cases we may be able to provide better information to help others.

Are the AT clinics still running?

At the moment both the children's AT clinic at Nottingham, and the adult clinic at the Royal Papworth Hospital in Cambridge have stopped seeing people face to face. They have replaced visits with consultations by telephone. We do not as yet know when they will be able to resume normal service.

In the meantime, if you have specific healthcare enquiries, you can continue to contact the clinics directly, or via the AT Society support@atsociety.org.uk or 01582 760733.

Should I continue to go to other medical appointments?

Here again, this is a case of using common sense. If the appointment is for something that requires or may require immediate treatment, you should discuss this with the appropriate medical contact first, for example, your GP, local hospital or outpatient service. If it is for a routine or non-urgent matter or check-up, you should seriously consider cancelling it. If in doubt, consult your GP or other medical contact.

I or other members of my family are suffering from anxiety and stress because of the Coronavirus situation. What can we do?

We know these are uncertain times and lots of people are understandably feeling anxious and worried, especially those who are taking 'social distancing' measures.

Staying at home for a prolonged period of time can be difficult, frustrating and lonely and some people might experience a dip in their mood. So now more than ever it's really important to remember to take care of your mind as well as your body.

Staying in touch with family and friends over the phone or on social media can help. So can thinking about ways to keep busy with activities at home such as, reading, online learning and watching films. If you feel well enough you could take part in light exercise within your home or garden.

The NHS have developed an online webpage, called Every Mind Matters – ONE YOU - with a short quiz to get a 'mind plan' which has been designed to help you feel more in control, deal with stress and anxiety, boost your mood and improve your sleep.

<http://bit.ly/nhseverymindmattersoneyou>

Please do keep checking our Facebook page for tips/ideas and information on how to look after your mental wellbeing and feel free to call us (during office hours) if you would like to

chat to someone or just talk things through, we are always happy to speak to you and there will always be someone on the phone during office hours.

If you really feel things are getting on top of you or you need to speak to someone urgently about a mental health issue - please go to this link <http://bit.ly/adviceonmentalhealth> or else call 111.

We will continue to add to this sheet as we receive questions. If you have a question not covered, or anything you want to talk about, please contact us at support@atsociety.org.uk or ring 01582 760733.

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