

**Department of Rheumatology
Scleroderma Clinic**

Prof Chris Denton Tel: 020 375 82042
PA for Scl Clinic Tel: 020 375 82042
Specialist Nurses Tel: 020 375 82042
Patient helpline Tel: 020 375 82042

Dr Voon Ong Tel: 020 375 82042
Dr E Derrett-Smith Tel: 020 375 82042
Pathway Co-ord Tel: 020 375 82042
Department fax Fax: 020 7830 2428, internal x 36884
Department e-mail rf.rheumatologyadmin@nhs.net

Date 30th March 2020

Dear Patient,

We are writing to you because you are someone at risk of severe illness if you catch COVID-19 (coronavirus). This is because you have a diagnosis of scleroderma. Many of you are receiving immunosuppressive medications which may also increase the risk and you may receive a separate letter from us to advise you on this.

We have enclosed a letter that sets out key advice for you for at least the next 12 weeks. **Importantly, we advise that the safest course of action is for you to stay at home at all times and avoid all face-to-face contact outside your household for at least twelve weeks, except for carers and healthcare workers who you must see as part of your medical care.**

During this time, we encourage you to keep in regular touch with family and friends in other ways, such as telephone or video calls.

We also wanted to set out some important changes we are making to the scleroderma service during the Coronavirus outbreak:

- We are postponing all currently arranged scleroderma outpatient clinic appointments during this period of increased risk for COVID-19. If you have an appointment during this time, you will be sent a re-arranged appointment. Please note that all lung function and echocardiogram tests have been postponed and these will be rescheduled at next available dates.
- If you need to contact us for specific medical or nursing advice related to scleroderma, please contact scleroderma nurse helpline service (**020 7830 2326**) or our secretary at **020 7830 2267**. We will triage the phone calls received and respond as quickly as we can, but please bear with us during what is a time of significant extra pressure. We have a reduced medical and specialist nursing team during this time due to staff redeployment. Please consider if you absolutely need to contact us before doing to help us provide a manageable service to you.

We are grateful for your understanding and patience. At this critical time, we will continue to review the situation regularly and our primary concern is to minimise risk to vulnerable individuals during this period.

We will be updating any further advice on our Royal Free Scleroderma website
<http://www.scleroderma-royalfree.org.uk/>

Yours sincerely,

Professor Christopher P Denton PhD FRCP
Professor of Experimental Rheumatology &
Consultant Rheumatologist

IMPORTANT: PERSONAL

Dear Patient,

IMPORTANT ADVICE TO KEEP YOU SAFE FROM CORONAVIRUS

Your safety and the continued provision of the care and treatment you need is a priority for the NHS. This letter gives you advice on how to protect yourself and access the care and treatment you need.

The NHS has identified you, or the named person you care for, as someone at risk of severe illness if you catch Coronavirus (also known as COVID-19). This is because you have an underlying disease or health condition that means if you catch the virus, you are more likely to be admitted to hospital than others.

The safest course of action is for you to stay at home at all times and avoid all face-to-face contact for at least twelve weeks from today, except from carers and healthcare workers who you must see as part of your medical care. This will protect you by stopping you from coming into contact with the virus.

If you are in touch with friends, family or a support network in your community who can support you to get food and medicine, follow the advice in this letter. If you do not have contacts who can help support you go to www.gov.uk/coronavirus-extremely-vulnerable or call 0800 0288327, the Government's dedicated helpline.

If, at any point, you think you have developed symptoms of coronavirus, such as a new, continuous cough and/or high temperature (above 37.8 °C), seek clinical advice using the NHS 111 online coronavirus service (<https://111.nhs.uk/covid-19/>). If you do not have access to the internet, call NHS 111. **Do this as soon as you get symptoms.**

You, or the person you care for, should:

- strictly avoid contact with someone who is displaying symptoms of coronavirus (COVID-19). These symptoms include high temperature (above 37.8 °C) and/or a new and continuous cough
- not leave your home
- not attend any gatherings. This includes gatherings of friends and families in private spaces e.g. family homes, weddings and religious services
- not go out for shopping, leisure or travel. When arranging food or medication deliveries, these should be left at the door to minimise contact
- keep in touch using remote technology such as phone, internet, and social media
- use telephone or online services to contact your GP or other essential services
- regularly wash your hands with soap and water for 20 seconds. Ask carers or support workers who visit your home to do the same.

The rest of your household should support you to stay safe and stringently follow guidance on social distancing, reducing their contact outside the home. In your home, you should:

- minimise the time you spend with others in shared spaces (kitchen, bathroom and sitting areas) and keep shared spaces well ventilated
- aim to keep 2 metres (3 steps) away from others and encourage them to sleep in a different bed where possible



- use separate towels and, if possible, use a separate bathroom from the rest of the household, or clean the bathroom after every use
- avoid using the kitchen when others are present, take your meals back to your room to eat where possible, and ensure all kitchenware is cleaned thoroughly.

If the rest of your household are able to follow this guidance, there is no need for them to take the full protective measures to keep you safe.

You will still get the medical care you need during this period. We are considering alternative options for managing your care and will be in touch if any changes are needed. Your hospital care team will be doing the same. We also advise that:

1. Carers and support workers who come to your home

Any essential carers or visitors who support you with your everyday needs can continue to visit, unless they have any of the symptoms of coronavirus. All visitors should wash their hands with soap and water for 20 seconds, on arrival and often.

It is also a good idea to speak to your carers about what happens if one of them becomes unwell. If you need help with care but you're not sure who to contact please visit www.gov.uk/coronavirus-extremely-vulnerable.

2. Medicines that you routinely take

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

1. Asking someone who can pick up your prescription from the local pharmacy, (this is the best option, if possible);
2. Contacting your pharmacy to ask them to help you find a volunteer (who will have been ID checked) or deliver it to you.

You may also need to arrange for collection or delivery of hospital specialist medication that is prescribed to you by your hospital care team.

3. Planned GP practice appointments

Wherever possible, we will provide care by phone, email or online. But if we decide you need to be seen in person, we will contact you to arrange your visit to the surgery or a visit in your home.

4. Planned hospital appointments

NHS England have written to your hospital to ask them to review any ongoing care that you have with them. It is possible that some clinics and appointments will be cancelled or postponed. Your hospital or clinic will contact you if any changes need to be made to your care or treatment. Otherwise you should assume your care or treatment is taking place as planned. Please contact your hospital or clinic directly if you have any questions about a specific appointment.

5. Support with daily living

Please discuss your daily needs during this period of staying at home with carers, family, friends, neighbours or local community groups to see how they can support you. If you do not have anyone who can help you, please visit www.gov.uk/coronavirus-extremely-vulnerable.

This letter is evidence, for your employer, to show that you cannot work outside the home. You do not need to get a fit note from your GP. If you need help from the benefit system visit <https://www.gov.uk/universal-credit>.

6. Urgent medical attention

If you have an urgent medical question relating to your **existing** medical condition, or the condition of the person you are caring for please contact us, or your specialist hospital care team, directly. Where possible, you will be supported by phone or online. If your clinician decides you need to be seen in person, the NHS will contact you to arrange a visit in your home, or where necessary, treatment in hospital.

To help the NHS provide you with the best care if you need to go to hospital as a result of catching coronavirus, we ask that you prepare a single hospital bag. This should include your emergency contact, a list of the medications you take (including dose and frequency), any information on your planned care appointments and things you would need for an overnight stay (snacks, pyjamas, toothbrush, medication etc). If you have an advanced care plan, please include that.

7. Looking after your mental well-being

We understand that this may be a worrying time and you may find staying at home and having limited contact frustrating. At times like these, it can be easy to fall into unhealthy patterns of behaviour, which can make you feel worse.

Simple things you can do to stay mentally and physically active during this time include:

- look for ideas for exercises to do at home on the NHS website
- spend time doing things you enjoy – reading, cooking and other indoor hobbies
- try to eat healthy, well-balanced meals, drink enough water, exercise regularly, and try to avoid smoking, alcohol and recreational drugs
- try spending time with the windows open to let in fresh air, arranging space to sit and see a nice view (if possible) and get some natural sunlight. Get out into the garden or sit on your doorstep if you can, keeping a distance of at least 2 metres from others.

You can find additional advice and support from [Every Mind Matters](#) and the [NHS mental health and wellbeing](#) advice website.

Further information on coronavirus, including guidance from Public Health England, can be found on the nhs.uk¹ and gov.uk² websites.

Yours sincerely,

Professor Christopher P Denton PhD FRCP
Professor of Experimental Rheumatology &
Consultant Rheumatologist

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

2 <https://www.gov.uk/coronavirus>