

Manchester pulmonary fibrosis virtual support group meeting 26/5/2020 summary of discussion:

This meeting had 27 attendees not including members of the ILD team at Wythenshawe.

Pandemic

Testing

Vulnerable people who develop covid symptoms can get a covid test by registering on the government website. More information about getting a test can be found here:

<https://www.nhs.uk/conditions/coronavirus-covid-19/testing-and-tracing/ask-for-a-test-to-check-if-you-have-coronavirus/>

Facemasks

We discussed following the current government advice on wearing a facemask in public. The latest press release at the time of the meeting can be found here:

<https://www.gov.uk/government/news/public-advised-to-cover-faces-in-enclosed-spaces>

At the moment, vulnerable people are still shielding, so should not be out in public anyway. Wearing a facemask may help to prevent unknowing carriers of the virus from spreading it.

Social distancing

Different countries have different rules about social distancing (2m vs 1.5m vs 6 feet) and the truth is the scientific community cannot definitively say what a safe social distance is. We recommend following the government's advice on social distancing as it is based on scientific advice.

Covid related lung disease

There was a question about whether people who had the covid virus would experience ongoing lung disease after their initial recovery. Preliminary reports show that some people have evidence of lung fibrosis, but we do not yet know how this will affect them in the long term. The ILD team is involved in following up this group of people and collecting information on this so we can understand it better.

Vitamin D

The official guidance for taking vitamin D has changed during the pandemic, and now those who are shielding are being encouraged to consider taking vitamin D as they may not have had enough daylight exposure and may be deficient. A dose of 10µg (micrograms) per day is a sufficient dose. Some people may already be getting this supplement alongside prescribed calcium replacements, or a multivitamin, so please check your other medications before starting this supplement. More information here:

<https://www.nhs.uk/conditions/vitamins-and-minerals/vitamin-d/>

Symptom management

Oxygen assessments

Some people monitor their oxygen sats at home and may notice a drop in this reading when they are walking around. This may be an indication that an oxygen assessment is required. For more information on oxygen therapy, the British Lung Foundation has this leaflet:

<https://shop.blf.org.uk/collections/lung-health-information/products/oxygen-booklet>

Cough

Cough is a common symptom of pulmonary fibrosis, and Tracey talked us through some simple home remedies which may help with this. Sipping drinks, sucking sweets (menthol can be drying but some people find the coolness of mint helpful) and nose breathing can help to suppress a cough. Taking 2 short, sharp sniffs can stop a cough before it begins. If your cough is productive, breathing techniques can help with sputum clearance. For some people, oxygen relieves their cough.

We are currently updating a leaflet on cough management and will send this out when it is completed.

Breathlessness

We talked about using a fan to help relieve breathlessness. Directing the draught at the side of the face may be more beneficial than having it face on. We recommend that everyone who gets breathless tries fan therapy. Some British Lung Foundation resources on this subject can be found here:

<https://www.blf.org.uk/support-for-you/keep-active/exercise-video/breathing-techniques>

<https://www.blf.org.uk/support-for-you/breathlessness/how-to-manage-breathlessness>

Staying active

We discussed the value of staying active for people with pulmonary fibrosis. Whilst it won't improve lung volumes, it is vital to stay active as part of overall health, including heart health and mental wellbeing. Staying active helps to maintain muscles, including the intercostal muscles (between the ribs) and the diaphragm, which are all used for breathing. The British Lung Foundation have put together some resources for exercising at home, which can be found here:

<https://www.blf.org.uk/exercise-video>

Chest Infections

Rescue packs

People have had different experiences of getting access to and using rescue packs of antibiotics. It is at the GP's discretion to prescribe rescue packs. Some GPs worry about giving rescue packs as it can delay people from reaching out to the GP when they are unwell, and can delay more appropriate treatment. There is also concern about overuse of antibiotics, which can lead to resistance, and harder to treat infections. The most common infections are viral, and cannot be treated with antibiotics, so getting an assessment is important. We generally advise the following:

1. If you feel you may benefit from having a rescue pack (e.g. you have regular chest infections, or you find it difficult to get an emergency GP appointment), discuss it with your GP
2. If you feel unwell and have symptoms of a chest infection (e.g. fever, change in sputum, generally unwell, more short of breath, feel "chesty") you should contact your GP in the first instance. If they are able to advise you by phone or assess you within a day or two, you should wait for this before starting treatment. If you feel worse while waiting for your assessment, contact the GP again
3. If you cannot get a quick appointment, or it is a weekend or holiday and you cannot get better advice, start your rescue pack. However, you should still arrange for an urgent GP appointment as soon as the surgery reopens
4. If you are no better after finishing your rescue pack, contact your GP again and be prepared to send a sputum sample
5. Remember to reorder your rescue pack if you have started it

Antibiotics

Please be aware that some antibiotics can interact with your antifibrotics, immunosuppression or other medications, particularly warfarin.

Viral infections

Most chest infections are viral which is why we sometimes delay the use of antibiotics. If you have a viral infection there is not any specific treatment for this, except for taking paracetamol and keeping your fluids up. Paracetamol is safe to take with your antifibrotics or immunosuppression, and is safe to take with oramorph, slow release morphine and codeine.

Antifibrotics

We were asked how we are able to tell if antifibrotics are working, and the reasons we would switch or stop treatment. It is difficult to tell how effective antifibrotics are for individuals as we don't have a clone to compare! We try not to switch treatment, and would only do so if we are worried about a decline in symptoms, or the patient is experiencing intolerable or severe side effects. We hesitate to switch treatment because we are not allowed to chop and change between the antifibrotics.

Pirfenidone and sun exposure rash

A photosensitive rash is a side effect of pirfenidone, and can be caused by exposure of the skin to any daylight. Anyone who is on pirfenidone should use factor 50 sun cream, with 4 or 5 star UVA/UVB rating, and wear a hat to reduce the risk of this. A reaction is more likely to occur just after taking treatment. This is not a dangerous side effect but it can take some time to heal, and it can reoccur. If you think you have this side effect, please contact the ILD nurses and we can support you.

ILD service at Wythenshawe

Phone contact

We are available by phone if you need to contact us, although our phone message has changed. If you need advice, please call 0161 291 4936 and listen to the whole message, which will direct you to who you need to call. Please don't hesitate to call; we realise it is a difficult time and are here to support you.

Appointments

Please do not attend the hospital for any face to face appointment, unless specifically advised to by a member of the team. There has been some confusion as people have received appointment letters, but unfortunately we are not allowed to run face to face clinics unless absolutely necessary. All appointments will be done by phone, with a view to introducing virtual clinics in the future. If you are unsure about your appointment, please contact us. We realise this will be disappointing for some people, but we are following the NICE guidance and have to do whatever we can to reduce the risk for people who have to come into hospital for urgent care.

We are looking to the future and asking for support in running face to face clinics from a "cold" site (where no covid patients are treated). We will also be trialling virtual clinics.

Our lung function suite at the hospital is not currently in use as lung function testing carries a high risk of spreading covid. This is significantly reducing our capacity for testing and we are working with the trust to resolve this. At the moment we will only be doing lung function testing if there is a concern about a decline in symptoms, or if it will inform us about changing treatment.

Research

Some of our members are involved in research studies relating to their disease. Unfortunately, we are unable to review and give details on results recorded in research trials (e.g. lung function tests), in order to protect the trial from researcher bias (i.e. from the research team being able to identify which participants are receiving the new medication and which are receiving the placebo) which can affect the results of the trial.

People who are involved in a clinical trial will still get their normal clinical follow ups where tests can be carried out and reviewed in the normal way.

Support Groups

Invitation to Tameside virtual support group

Clive and Sue Green have kindly welcomed anyone who is interested to attend their virtual support group. Their poster is below; please contact them for more information.



If you are running a virtual group of any kind for people with pulmonary fibrosis or ILD and you would like to publicise it on our newsletter, please get in touch with us and we will include it in the future.

Peer support for new technology

We know that for some people, getting to grips with new technology can be challenging. We are looking for volunteers who are confident with using new technology and apps such as Zoom, who would be able to help set up one or two others and support them with it by phone or email. If you think you might be able to help, please email us at ildnursemanc@mft.nhs.uk.

Equally, if you would like to join in our virtual support group but do not feel confident using Zoom, please email us at ildnursemanc@mft.nhs.uk (or reply to the email this newsletter was attached to) and we will try to match you with someone who can support you.

Contact Us

Interstitial Lung Disease Consultants

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ILD Specialist Nurses

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ILD Pharmacists

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Next Meeting

Our next meeting will be Thursday June 25th at 2pm, via Zoom. The topic will be medications and will be hosted by our ILD pharmacist Kate. If you have a question on this topic, please submit it beforehand to ildpharmacymanc@mft.nhs.uk so we can look into it for you before the meeting.

Here is the meeting link: <https://zoom.us/j/91374383907>