

Manchester pulmonary fibrosis virtual support group meeting 25/6/2020 summary of discussion:

This meeting had 40+ attendees not including members of the ILD team at Wythenshawe.

## **Next Meeting**

Our next meeting will be Thursday July 30<sup>th</sup> at 2pm, via Zoom. The topic and speaker are not yet confirmed so we will announce this nearer the time. The meeting is accessed through this link:

<https://zoom.us/j/96738882591>

## **Shielding Guidelines**

The government has extended shielding for extremely vulnerable people until the end of July. It has relaxed some of the shielding rules from the 6<sup>th</sup> July. People who are shielding can now meet in groups of up to 6 outdoors and form a 'support bubble'. The full details are here:

<https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>

We discussed how in the future the government may pause shielding but bring it back if we have a second wave.

In WALES the government advice is different, and they advise you can exercise outside / meet outside with people from another household whilst 2m apart. You should continue to shield from others you live with if they are not shielding also. They advise not to go to the shops or to work until 16<sup>th</sup> August.

### **Returning to Work**

If we reach 1<sup>st</sup> of August and you do not feel safe to go back to work, you must try to make a plan with your employer which you feel happy with. They need to arrange for you to work from home if that is possible, otherwise they must protect you e.g. changing shift times or working patterns and identify all areas of risk and make plans for how to minimise all of these.

If you don't think your employer is taking all practical steps to promote social distancing, you can report this to your local authority or the health and safety executive.

If you need advice about work disputes you can approach ACAS. Citizens advice also have an information page on this on their website:

<https://www.citizensadvice.org.uk/work/coronavirus-if-youre-worried-about-working>

If you don't WANT to go back to work and you are furloughed this can be extended. If you are not furloughed then you can ask to take annual leave, unpaid parental leave if this applies to you, or sick pay.

## **Covid**

### **Antibody tests**

Currently healthcare professionals and other groups who have been at high risk of exposure during the pandemic have been offered antibody tests which can show if they have had the virus. We are not yet sure if having antibodies means you're immune to getting the virus again, and we do not know if people keep antibodies over time, but research is focussing on this. Some people mentioned that it is possible to access antibody testing privately.

You can see a review about antibody tests in the British Medical Journal via the link below and we have included some extracts from this article at the bottom of this newsletter:

<https://www.bmj.com/content/369/bmj.m2284>

### **Vaccination**

We don't have much fresh information on a vaccination for covid-19 yet. On Thursday before the meeting there was some advice published which suggests people with ILD will be included in the first cohort of people to be invited to have the vaccination:

<https://www.gov.uk/government/publications/priority-groups-for-coronavirus-covid-19-vaccination-advice-from-the-jcvi>

There are still many unknowns e.g. whether we will get a safe and effective vaccine, whether if effective it will be effective for all groups of people (e.g. does age change this or medical conditions), when it may become available if we do, what age groups it will be licensed for, the dosing schedule i.e. whether it will be a one-off dose, how many doses will initially and subsequently be available to the NHS, how long it will confer protection for, what side effects it might have, and who might not be able to have it due to development of a serious side effect in those people (contraindicated).

## **Pollen Count**

We talked about whether a high pollen count can affect your breathing, and it was generally agreed that people notice that it does affect them. Antihistamines are available without prescription and taking one daily may help ease this. Some people also find that using local honey every day can build a tolerance to local pollen and therefore may reduce this reaction.

## Lung Function

The capacity for doing lung function testing at Wythenshawe has decreased massively and the lung function team are only seeing about 10% of their pre-covid caseload. Unfortunately, this means you will not be invited to have a lung function test as regularly as we were previously doing them. The hospital is looking at ways to continue to increase capacity, and we are still able to get tests for those who are in need.

Lung function testing is only one way of assessing your lungs. Breathlessness, oxygen use at home, and how you are managing in general all give us information about your lungs and are often more sensitive and accurate than breathing tests. We would not routinely send you for a CT scan to assess progression of your illness unless we were considering changing treatment.

## Medications

### **Antifibrotic deliveries from Polarspeed**

If anyone is having problems with deliveries from Polarspeed, their phone number is 0800 7833178. They have moved recently to a new site and there have been some teething problems; we can only apologise on their behalf. If you can't resolve problems with them, please phone us and we can help.

### **Interactions**

Please check if you start a new medication whether there is an interaction with your ILD medications. Check with the person prescribing the new medicine, or you can also ask us here.

Remember supplements including herbal preparations can also interact. It can be harder to find information about interactions with supplements as they do not have the same licensing from the MHRA. We would usually advise against unlicensed supplements for this reason.

Sometimes we can find no information to help us determine if there is an interaction. Sometimes we identify a possible mechanism for an interaction but cannot give you detail about how important that interaction might be.

*Remember: the supplement may not only interact with your ILD medication!*

### **Medication and sun cream**

If you are taking pirfenidone or immunosuppression, you should use sun cream with SPF 50. When shopping for sun cream, look for a "broad spectrum" sun cream which protects you from UVA and UVB rays. The SPF number refers only to UVB protection. UVA protection is indicated by another figure and your sunscreen will not be broad spectrum unless you have adequate UVA protection. Packaging may have 5 stars printed on it, or UVA with the A in a circle, or PA +++.

Re-apply every 2-4 hours and about 20 minutes before you go out. Also protect yourself with clothing and a hat.

Pirfenidone is known to cause skin rashes related to daylight exposure; if you are taking this medication and think you may be experiencing this side effect, please call us so we can help to resolve this.

### **Prednisolone and osteoporosis**

We had a question about the risk of osteoporosis with prednisolone use. The answer to this is based on a balance of risk for which there are several factors.

In order to calculate this, we do have a risk assessment tool, and this can be found at the address below:

<https://www.sheffield.ac.uk/FRAX/tool.aspx?country=1>

If you know the answers to the questions in the tool, press calculate, and then press “view NOGG guidance” this will plot your risk on a chart. There should be 2 crosses, one for a prednisolone dose 2.5-7.5mg and one for a dose higher than 7.5mg daily. However, the risk differs dependent on your dosage of prednisolone and your risk may be higher than you see on the chart. This makes the question difficult to answer.

If you would like to read further about the topic there are some guidelines at (specifically section 8):

<https://www.sheffield.ac.uk/NOGG/NOGG%20Guideline%202017.pdf>

### **Nintedanib**

Bloating and indigestion are common side effects of nintedanib, and some ways to avoid them include ensuring you take nintedanib during a meal, sitting upright for 2 hours after a meal, and treating indigestion either with a prescribed treatment such as omeprazole or lansoprazole, or with an over the counter treatment like Gaviscon.

### **Green tea**

Someone asked a question about green tea, and we talked about the potential for this to interact with other medications. We have included more detailed information on this at the bottom of this newsletter.

## **Research**

### **Atlas study**

The Atlas study is researching whether pirfenidone is effective when inhaled through a nebuliser, to see if there is a local action rather than when it is swallowed as tablets. We have quite a few patients here at Wythenshawe involved. These will only have been people who we cannot treat with usual medicine choices due to them not being eligible or they have not been able to tolerate them. There are strict criteria for who can join each trial, and so there is for the Atlas study.

In terms of results from the Atlas study, we are looking at whether your FVC (forced vital capacity is how much air you can breathe out of your lungs when you force the breath out) is maintained (as we are looking for with the oral pirfenidone), and also whether your DLCO (gas transfer) percentage is maintained, and whether there are any changes in your cough frequency or intensity. A CT scan will look at lung volume and scar tissue at a couple of points during the study. We want your results to stay as stable as possible. You can also judge partly how it is working by how you are feeling in yourself, and whether you are more breathless, or having any side effects. Your results can be discussed at your follow-up appointments.

## **Satellite IPF service at Bolton- some progress!**

Steve Milward has made some progress in getting a satellite service set up in Bolton, which will provide nursing care closer to home for people with IPF, including pirfenidone and nintedanib monitoring. We already have similar support in other areas such as Wigan, Chester, Blackburn, Preston and the South Lakes. This is a project that the nurses at Wythenshawe and Bolton have wanted to push forward for a long time but have had little success, so it really demonstrates the power of “the patient’s voice” when it comes to making changes in healthcare. We want to say thank you Steve, for your tireless work and persistence in making this happen.

## **Zoom Tips**

We have all had to get to grips with new ways of communicating over the last few months. We would like the virtual support group to be a place where you feel comfortable to interact with us and each other and we want to keep it relaxed and informal. This is very hard to achieve in an environment where only one person can talk at a time! Zoom has some functions which can help make large meetings run a bit more smoothly, and we encourage you all to try them out:

1. **The Raise Hand button:** this button indicates to the speaker that you have a question or comment to make and ensures everyone gets a chance to speak
2. **The Thumbs Up button:** a nice function that tells the speaker you agree with and support their comment
3. **Chat:** you can send messages to everyone in the meeting via the chat function, without interrupting the speaker. You may have a useful link, want to share your experience on the subject, or ask a question. You can also chat directly to each other using this function, so you can say hi to anyone you recognise!
4. **Mute:** the most important function on Zoom! Please mute your microphone if you’re not speaking. The hosts may mute you if you forget; please don’t be offended by this, we are trying to reduce noise and interruption

## **ILD service at Wythenshawe**

### **Phone contact**

The whole ILD team are now back on their normal numbers, which are below. You can also contact us by email if you prefer. Please be prepared to leave a message.

### **Appointments**

Please do not attend the hospital for any face to face appointment, unless specifically advised to by a member of the team. We are still not running face to face appointments unless for a necessary, urgent consultant review. We are waiting to start virtual clinics which will run through an app called Attend Anywhere, and we will have more information about this in the future.

## 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 [ildnurseman@mft.nhs.uk](mailto:ildnurseman@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 [ildnurseman@mft.nhs.uk](mailto:ildnurseman@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**

Secretaries 0161 291 5054 Fax 0161 291 5602

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### **ILD Specialist Nurses**

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### **ILD Pharmacists**

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Website: [www.northwestipfmanchester.weebly.com](http://www.northwestipfmanchester.weebly.com)

For enquiries about Pirfenidone and Nintedanib deliveries, please contact Polarspeed on 0800 783 3178

## More information

### **Antibody tests**

How accurate are the lab tests?

There are two key measures of an antibody test's quality: its sensitivity and specificity. Highly sensitive tests can accurately detect whether people have antibodies present in their blood. If a test is described as highly specific, this means that it's specific to a particular type of antibody and can also reliably detect people who do not have covid-19 antibodies. The presence of some types of antibodies can give an indication of when a person may have been infected.

So far, the quality of antibody tests for covid-19 vary in quality, but several offer sensitivity and specificity near to or even at 100%, say their manufacturers.<sup>2</sup> Very occasionally, an antibody test may give a false positive result (suggesting that people have covid-19 antibodies when in fact they do not) because of cross reactivity with coronaviruses other than SARS-CoV-2, for example.

No test can always be 100% accurate. Lab test kits made by the drug companies Roche and Abbott were evaluated by Public Health England in a series of experiments using samples from confirmed covid-19 patients. Public Health England found that the Abbott test was 93.4% sensitive and 100% specific for samples collected two weeks after the patient first showed symptoms.<sup>3</sup> The Roche tests were 87% sensitive and 100% specific.<sup>4</sup> The lower the sensitivity, the higher the likelihood of false negative results.

Does a positive antibody test result mean I'm immune?

This is the question on most people's minds, but they shouldn't get their hopes up, says Simon Clarke, associate professor in cellular microbiology at the University of Reading. "There's been far too much said about immunity passports and [the suggestion that] 'if you've got antibodies, you're immune,'" he says.

Scientists still don't know what an ideal immune system response to covid-19 looks like. Antibodies may be very important, but so may the response of T cells, for example. It's possible that merely having antibodies isn't enough to prevent reinfection by the virus. And antibodies may also gradually disappear from someone's system over time—perhaps after a few months or years—potentially leaving that person vulnerable to SARS-CoV-2 again. Our immunity to the seasonal flu tends to last for about a year, but it's still unknown whether covid-19 will be the same, longer, or shorter.

And, as we've heard, the accuracy of antibody tests is still under review in many cases. People may get a false positive result showing that they have antibodies and may relax their attitude towards handwashing and social distancing.

"People are interested in these tests because they want certainty," says Riley. "The problem with the individual tests is they cannot give them that."

### **Green tea**

Information is from an electronic Herbal Medicines Database. Green tea is very well studied and there is a large body of literature reporting the pharmacological actions of it and its constituents but there are no studies in lung disease except lung cancer.

Green tea contains:

alkaloids including caffeine, and smaller amounts of xantines (including theobromine and theophylline)

tannins including theogallin and trigalloyl glucose  
theanine, vitamin c and minerals

but the precise composition of green tea (unfermented tea leaves) vary with the geographical location, conditions and time of harvest as well as the manufacturing process.

Green tea is used in Chinese medicine, and there are oral supplements which may contain very high doses of the plant leaf chemical constituents.

There is data on adverse effects, and some studies have associated it with toxic effects to the liver, kidneys or gastrointestinal tract. The database discusses a review of 34 cases of hepatitis following the consumption of green tea preparations for weight loss, and 2 cases of liver damage involving consumption of a green tea product for glaucoma. Mixing green tea infusions with contraceptives or similar hormone preparations seems to increase the risk. Side effects are more likely at EGCG (epigallocatechin gallate) doses above 800mg per day but it is not possible to identify a safe dose. We would not recommend taking green tea supplements.

In terms of drinking green tea made with everyday teabags, due to the amount of caffeine, people with cardiac diagnoses are advised to limit consumption to a maximum of 2 cups a day.

People with existing liver or gastrointestinal conditions should probably not drink large amounts of green tea.

Green tea might cause a small increase in blood pressure and may reduce blood levels of some betablockers. Green tea might have some antiplatelet effects which may be additive if already taking antiplatelet drugs e.g. aspirin/clopidogrel and may reduce the INR for people on warfarin. It could increase the blood levels of simvastatin, decrease blood levels of digoxin, increase blood levels of sildenafil, and reduce blood levels of folic acid. This list of interactions is unlikely to be exhaustive.

Because green tea can reduce blood levels of sunitinib, and this is related to nintedanib, we would advise against using green tea with nintedanib in case the same interaction may occur.