

Manchester pulmonary fibrosis virtual support group meeting 30/7/2020 summary of discussion:

This meeting had 34 attendees.

Dr Chaudhuri dedicated this meeting to Caroline Birchwood who very sadly died check when make sure name right the group send their condolences to her fiancé, family, and friends. We had a few moments of silent thought.

Next Meeting

Our next meeting will be Thursday September 10th at 2pm, via Zoom. Our speaker will be Sam Roberts, who is the Respiratory Team Leader from the Countess of Chester, who will be talking to us about staying active whilst living with pulmonary fibrosis. We will email out the zoom link a few days before the meeting.

Speaker – Zoe Mitchell from Age UK

Zoe talked to us about Age UK day centres, homecare and aging well, she talked about keeping active and in touch with communities and to try and avoid people being lonely or feeling isolated. She told us a bit about what services were offered pre covid.

This included an aging well group for lonely or isolated people with activities including gardening, make and mend, art, and access to a library. Some sites have an over 50s gym.

Since covid things are opening up whilst maintaining socially distancing guidance. Running a food bank, delivering food parcels, boredom busters and access to an advice team over the telephone

Q: Are the shops reopening

A: Yes, some have reopened and some planning to reopen.

Q: what is in the Gym

A: the south Manchester gym has an arm pedal bike, gentle resistance training equipment there is a gym instructor who carries out and induction and armchair exercise programme.

Thank you to Zoe for coming to talk to us.

Further information about AGE UK and what is available for you can be found here <https://www.ageuk.org.uk/>

The next section of the meeting was led by Dr Chaudhuri and was a question and answer session. Thank you to everyone who send us questions before the meeting.

Please note this is general advice and was given prior to further restrictions being placed on areas across the North of England, as the new restrictions are lifted please use the below as general advice.

Please see link for updated advise for some areas across the north of England

<https://www.gov.uk/guidance/north-west-of-england-local-restrictions-what-you-can-and-cannot-do>

Q: I want some clear guidance about lifting shielding

A: Shielding has been paused, we advise if possible stay at home, if you need to work try and work from home if possible, it remains especially important to continue to socially distance. We advise if you need to go to the shops try and pick times that you know it will be quiet, use home delivery supermarket services or click and collect.

General advice;

- Stay at home
- Get shopping delivered
- Although shielding is paused the risk is not zero
- Keep up to date around your area, as we know in the last 5 days the rules can change very quickly. Your immediate local area may have different restrictions or guidance for you to follow.
- The situation will be fluid for a while
- Social distancing and washing your hands are key.

Q: Should we wear a mask?

A: We strongly encourage everyone to wear a face covering but we understand that it might be too difficult. Face coverings can be uncomfortable especially when you first start wearing them, we advise you practise wearing them inside the house to get used to how it feels, try different types of face covering/different material, and see which you find most comfortable. Face coverings can protect you somewhat, take them off using the straps and wash your hands thoroughly.

If you truly cannot wear a face covering you could consider a face shield.

For further information

<https://www.blf.org.uk/support-for-you/coronavirus/what-should-people-with-a-lung-condition-do-now/face-coverings>

<https://www.actionpf.org/information-and-support/coronavirus/faqs>

Q: Can I have my cleaner back?

A: Yes if you are comfortable with them in your house. It would be worth chatting to them about hand washing, wiping door handles when they leave a room and wearing a mask. Make sure you maintain a safe distance.

(Please note new restrictions in some areas of the north of England you will be able to do the above in some areas but not others until restrictions are lifted)

Q : Can we have our grandchildren to stay? Is it risky?

A: The more interactions you have the more you put yourselves at risk and although some restrictions have been lifted there is still an existing risk. We cannot say to you not to do it. If they do come make sure you all maintain good hand hygiene, have plenty of tissues around so if the cough or sneeze they can catch it in a tissue and bin it then wash their hands.

Q: We have family coming over from Dublin, can they meet in the garden.

A: Yes in the garden, please continue to socially distance, riskier indoors and we know less risky outside. It is low risk to meet like this but not negligible (apart from then there are temporary enhanced restrictions in place)

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Here is the government link to follow once local restrictions for some of us are lifted.

<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>

Q: Is it safe to have a takeaway?

A: Yes, all restaurants and takeaways should be adhering to covid guidance, if your food is being delivered the driver should knock them move away for the door. Take your food out of the box or bag then wash you hands

Q: Is it safe to go swimming?

Yes it is safe to go swimming, there are a few general rules including come to the pool ready, you should get your own area to leave your clothes, use your own lanes and apparently no butterfly!

Below are a couple of links to stay safe when going to the pool from swim England and government

<https://www.swimming.org/swimengland/pool-return-guidance-documents/>

<https://www.gov.uk/government/news/government-announces-gyms-and-pools-to-reopen-safely>

<https://www.pwtag.org/e-newsletter/>

Q: Do we know what is happening about the flu vaccine?

A: We know that there should be some clearer guidance coming out soon and GPs are working together looking into the best way to deliver this. There will probably be different ways of doing this in each area.

Q: Who is prioritised for a flu jab?

A: The flu vaccine is prioritised according to risk factors i.e. patients with diabetes. Patients with pulmonary fibrosis are vulnerable therefore should be prioritised. Please keep asking your GP if you are having problems accessing it using the term extremely vulnerable.

Q; what will it be like getting the flu vaccine?

A: There will be a lot of cleaning and re-gowning up between patients so the process will take longer, they may choose to use outdoors with tents, cars or drive through. One of our group tells us that this is already happening in some areas and blood tests and injections are carried out in the patient's car.

Q: We are meeting in a venue with 15-20 family members is that ok?

A: Much more at risk indoors and vulnerable patients should avoid more than 1 family at a time. We cannot guarantee this would be safe. We can only advise you of the risk, you can weigh up whether the risk outweighs the benefits. If you do meet minimise the risk as much as possible.

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Q: Grandchildren and hugging.

A: We understand how very hard it is not to give them a big hug but if possible, it is better not to hug to minimise risk, contact with others puts you at increased risk.

Q: What is happening with pulmonary rehabilitation?

A: This is difficult to answer as services differ in each area you live in. The British Thoracic Society has very recently helped by publishing some guidance for PR groups to restart services safely. Some groups are using a combination of sending out paper exercise sheets and calling you or providing access to virtual groups. Niall from Bolton has very kindly offered to share a link to his you tube channel with exercises for you to undertake.

Here is the link <https://www.youtube.com/playlist?list=PLIVbLv4jle5VhcxAiN7fGgS2UGuT3oTho>

Q: Should there be notification when buying a theatre ticket if the production is using Haze?

A: it can cause irritation but is not harmful. It may make you feel uncomfortable. It might be worth checking with the theatre first however it would not be used if it were harmful.

Apologies from Helen everyone I cannot find the BLF blog about haze

Q: Can I have my diabetic eye check?

A: Yes, opticians will wear full PPE, mask gloves and gowns and there will be a limited number of people allowed in the shop, if you need to go to the dentist they will also wear full PPE. It was good to hear of the groups experience in the optician who confirmed that they had felt very safe.

Q: What is happening in lung function?

A: We are now increasing our lung function activity at Wythenshawe, ILD patients are prioritised, if you are called for a lung function it is because we need you to have one. If you are stable we will not bring you in for lung function as regularly as we used to. It was very good to hear from one of the group who had been to Wythenshawe for a lung function and had confirmed that they had felt safe.

Hospital appointments in general here are different, we are spreading out the appointments by 1 hour if you arrive the clinic team will send you back to your car and ring you when they are ready. You are probably not able to have lung function and appointment on the same day, this is to stop patients having to wait around the hospital for any period of time to keep everyone safe.

Q: Can pets have COVID?

A : Yes there has been a recent case in the news. Vets are advising not to pet them as much and wash and sanitise your hands. There have been more cases in Spain

We brought the meeting to a close here, Thanks Dr Chaudhuri and to all participants for the great questions.