

Minutes from meeting 10/09/2020

36 people attend the meeting and a support group.

Agenda:

2:00: Brief introduction, discussion of the future of the local support groups

2:10: Jo Ruck from Action for Pulmonary Fibrosis will discuss Pulmonary Fibrosis Month and the charity's Shout Out campaign. She will also introduce the charity's new 'please give me space' lanyards that are designed to help people with fibrosis, and their carers, when they are out in public places

2:20: Sam Roberts will give her talk about staying active

2:50: We will talk briefly about the new virtual clinics we are starting and ask David and Clive to give their feedback from when they tested the software for us

3:00: Dr Rivera and the ILD team will be available to answer any general questions

Introduction.

We were sorry to start another meeting with bad news, but since we last met, we have lost another member of our group. Caroline Dillon was involved in 3 support groups; West Cheshire, Chester and our group in Manchester and looked after the Facebook pages for these groups, so many of you will have come across her. She sadly died last month after a short stay in hospital. We know she has given a lot of support to other group members over the years, and we really valued her input into the support group here and will sorely miss her.

We would like to keep Caroline's legacy going and continue with patient led support on social media. We will also need people to help lead and organise face-to-face support groups when it is safe to resume this. This includes thinking about re-launching a Manchester group to continue the legacy left by Dennis Barber, who we sadly lost in April. If you think you might be up for the challenge, Jo at Action will hopefully be able to support you with this, as well as the nursing team here and I'm sure the group's leaders from our other local groups can give advice.

Jo Ruck - Action for pulmonary Fibrosis

Echoed the sentiments above.

Reiterated that she would support people going forward if anyone is interested in leading the support groups.

Jo discussed The new '**Please Give Me Space**' lanyards/cards to alert others to the need for social distancing are now available to order (or print) via the website www.actionpf.org or by email info@actionpf.org or phone 01733 475642.

The lanyards are free of charge, but donations can be taken if you wish.

PF awareness month.

The charity is urging everyone involved in PF to write to their MP about ending restrictions on antifibrotics <https://www.actionpf.org/get-involved/awareness-month/shout-out>

At the end of September action for Pulmonary Fibrosis will send out a detailed letter to Matt Hancock and NICE chief executive about the above.

Still time to create a stir <https://www.actionpf.org/get-involved/awareness-month/create-a-stir> and raise money with a virtual get together.

Thanks to Jo

Staying Active talk Sam Roberts

We were very pleased to welcome one of our colleagues Sam Roberts who is the Respiratory Team Leader at Countess of Chester hospital. Who echoed the words about Caroline, she worked closely with Caroline developing support groups.

Sam spoke to us about activity, exercising safely, how much exercise to do and pacing.

Exercise can be difficult when you are breathless we all recognise that over the last 6 months while you have all been shielding/restricting your contacts you may not have been as active as you used to be which can make shortness of breath symptoms worse which can be frightening.

Lessening of activity slowly drops; you don't always know that it is happening, muscles become less fit needing more energy which can make you feel breathless. COVID has made this more likely to happen and we can all be more deconditioned due to this.

This is a cycle which you can try and break.

Remember being short of breath is normal.

Exercise is beneficial, it strengthens muscles, helps flexibility and circulation. Moderate activity is important to increase confidence and self esteem. Feeling better can help you're sleeping patterns, staying active can improve balance and posture.

Exercising Safely

You might need to have a quick chat with GP or practise nurse if you have any other health conditions before starting.

Start exercising slowly and build it up gradually making steady progress. Remember to warm up first. Important to make sure that you are breathing through exercise

Question: about Pilates and whether that was good exercise?

Answer: yes, it can be good as Pilates classes also talk through breathing control

Here is a link to patient leaflets about exercise and breathing techniques

<https://www.acprc.org.uk/publications/patient-information-leaflets/>

The below link is the British Lung Foundation link with a screening questions before you start which means you will be given the correct set of exercises for your ability.

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

Motivation to get started:

Include exercise into you normal daily routine, it does not have to be a half an our session you can do some exercises whilst you are doing your usual daily routine for example pushups on the kitchen units or an extra step up on the bottom step.

How much is too much and how little is too little?

Use a scale of 0 to 10

0 - little ————— x ————— x ————— 10 - worse ever

Try and work to level 3-4

Level 3-4 is the level that you know that you are out of breath, but you can still speak. Anything above that is too much. When you are exercising at home measure using your breathlessness as a guide rather than sticking to numbers of repetitions.

Sam told us a simple way of making weights using plastic milk bottles (meaning you have a handle to hold them more comfortably)

A 1-pint carton equals about 0.6kg

A 2-pint carton equals about 1.2kg

A 4-pint carton equals about 2.8kg

Ideally you should incorporate arm exercises as well as leg exercises into your exercise routine. Arms are equally important to exercise because many daily household tasks involve you using your arms for example making the bed, carrying the shopping, showering and washing your hair. These are some of the tasks that can make you breathless which all use your arms.

Set yourself goals make them realistic; it will help you keep up your exercise and keep you on track.

Pace yourself It is important to balance activity and rest

Some things are difficult to do when you have a health condition that affects your lungs. Please look at the information sheet "From waking to going to bed" that we have attached to this email to help identify some of the things you might find difficult and tips to do them differently.

Question- will I get back to my usual?

Answer it does not take long to lose your exercise tolerance, but it can take a long time to get back to some activity.

Thanks, you very much to Sam for speaking to us today.

Virtual Clinics

We have started to use virtual clinic appointments for some patients, if you are interested email the nurses ldnurseman@mt.nhs.uk

We asked David and Clive to try them out and report back to us what they were like.

David and Clive told us that the log on was a link similar to Zoom. They advised us to allow a few extra minutes before the appointment time as you need to answer a few questions before you get through to the waiting room. They found it easy and better than the telephone, David said it was nice to be able to see people.

You get a letter and in it is the link. The letter also tells you what to do.

Both David and Clive recommended Virtual clinics reiterating it was as easy as a zoom meeting.

Katie explained that as a team we are all adapting to new ways of providing clinic appointments, we hope that we will offer telephone, virtual and face to face if needed. We will keep you all updated.

Now over to the Q and A session with Dr Rivera, Dr Yioe and Dr Chaudhuri.

Question; should we have our vaccinations Inc flu and shingles.

Answer Pneumococcal vaccine (usually a once off vaccine) and the annual flu vaccine should be given. Flu vaccination should have started this month.

Please see link to patient information for the shingles vaccine which includes information on eligibility (caution if you are already prescribed immunosuppression treatment because the shingles vaccine may not be appropriate, please discuss this with your GP or contact the ILD team):

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/697573/Shingles_leaflet.pdf

<https://www.nhs.uk/conditions/vaccinations/shingles-vaccination/>

Some other vaccines (live vaccines) may not be suitable if you are prescribed immunosuppression please discuss this with your GP or the ILD team.

Question; when will clinical trials be starting again?

Answer We are slowly opening our clinical trials and continue to follow up patients in current trials. We hope in the next few weeks we might be able to open for new trials, but this will be dependant on any guidance over the next few months.

We have an email address that you can email to add your name and details to if you are interested in clinical trials ildresearch@mft.nhs.uk

Useful links

<https://www.blf.org.uk/support-for-you/keep-active/how-active-should-i-be>

<https://www.blf.org.uk/support-for-you/keep-active/pulmonary-rehabilitation>

<https://www.blf.org.uk/support-for-you/keep-active/what-activities-can-i-do>

The ILD team left the meeting so that the chat could continue.