

Support Group Meeting notes 12/3/21

Our guest speaker was Dr Sarah Chamberlain-Mitchell, Senior Lecturer in Physiotherapy from MMU. She talked to us about cough, non-medical treatments which might help to treat cough, and the research project she is working on which will investigate cough in ILD. Her talk was really interesting, and we had a lively Q&A, which I have summarised below

When we cough, our vocal cords open and close, and if we cough regularly, this can cause pain, inflammation, and a hoarse voice. Coughing all the time can have an impact on quality of life. Studies have shown that people with IPF have hypersensitive cough triggers; this means it takes less for them to cough and they cough for longer.

Sometimes we can identify other factors which are contributing to a cough. Asthma, rhinitis, post-nasal drip and reflux can make a cough worse and treating these can help to relieve cough. Some medications are known to worsen cough.

Non-medical treatment for cough

Education- understanding about cough sensitivity, what triggers cough and that there is a voluntary element to a cough can help to control it. It is important to know whether a cough is dry or productive- if you cough phlegm/sputum up from your lungs you should not try to suppress your cough, as coughing to clear your chest is beneficial.

Suppression- sipping water can help to hydrate the vocal cords and interrupt the cough trigger. Sucking boiled sweets can have a similar effect, but cough sweets can actually worsen the cough so plain boiled sweets are often more effective.

Reducing caffeine to 2-3 cups of caffeinated tea or coffee per day can have a positive effect on a cough as caffeine is an irritant.

Q&A

Q- I have been using a facial steamer every day whilst using oxygen and feel that my cough has decreased- do you think this is a good thing to use?

A- The steam can help with hydration which may be the reason this works. Nasal washouts can have a similar benefit. Oxygen can be drying and aggravate the cough

Q- I have a mixture of dry and productive coughs- should I be trying to clear my chest or suppressing my cough?

A- You should work to clear your chest when your cough is productive- often this is most noticeable in the morning due to your breathing pattern changing and going from lying to sitting/standing. You can suppress your cough when it is dry and tickly

Q- my cough starts when I move around, and productive of phlegm from my chest. I also have a constant runny nose. What will help this?

A- You should practice chest clearance exercises and consider getting treatment for rhinitis (runny nose) and post-nasal drip

Q- My cough is worst at night when I'm lying down. I use codeine linctus but it still stops me from sleeping, what can I do?

A- Sleep more propped up, try purse-lipped breathing techniques. Sometimes there is an element of expecting to cough at certain times, which can make it worse. Its hard to try to not think about coughing!

Q- My diagnosis is sarcoidosis and my cough was so bad I couldn't talk. Steroids helped initially but the effect wore off. When I was prescribed a fostair inhaler it made a huge difference to my cough. If I were to join a study about cough, would I need to stop treatment?

A- Any research study would be on top of treatment and there would be a set of tests performed before and after the study to see if it had any effect

Q- my diagnosis is hypersensitivity pneumonitis. I cough for 2 hours a day and I am finding that I need my oxygen more. I use oramorph to suppress my cough, but it is often productive. I have tried a nasal rinse, but I couldn't stand the salty taste. I am under the chronic cough service and am awaiting a review by the speech and language therapists. My cough is getting me down, what should I do?

A- you need more tailored advice and you are on the right path for getting this. Please raise these issues at your next specialist appointment

Q- I have previously been recommended Fisherman's Friends to help my cough- should I switch these to plain boiled sweets?

A- medicated sweets can dry the vocal cords, whereas plain sweets help to produce saliva. Sucking sweets can also provide a distraction

Q- I take long-acting morphine tablets and oramorph as needed. I have a productive cough in the morning, and it is dry later. My cough is irritating, and I find coughing tiring. Sometimes I wake in the night coughing and this can make me panic.

A- Opioids like morphine have some effect in cough- and researchers are looking for more effective treatments. Using breathing techniques like pursed lip breathing and chest clearance methods can help alongside medications

Some members of the group mentioned other things which have helped their cough:

- Lemon and ginger tea
- Liquorice tea
- Codeine

Action for Pulmonary Fibrosis

Jo from Action for Pulmonary Fibrosis updated us about a survey they are currently running. They are interested in what patients, relatives and healthcare professionals think should be the priorities for research into pulmonary fibrosis. If you are interested in having your say about the future of research, please follow this link for more information:

<https://www.actionpf.org/research/james-lind-alliance>