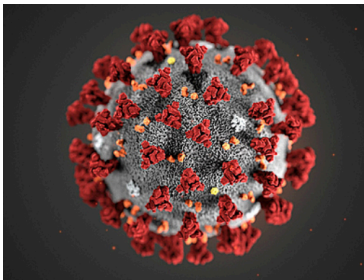


Norfolk & Norwich Pulmonary Fibrosis Support Group

Spring Issue – March 2020



I am writing this with one eye on the Government advice, regarding the current Coronavirus pandemic. The last couple of weeks have seen some major changes to the way we live across the country and I'm sure many of you are concerned about the implications, both in terms of the risk of picking up the virus and with regards to what is happening with your usual respiratory follow up.

We have all been advised to limit the amount of contact with others and to strictly keep to the recommendations regarding 'social distancing'.

Those over the age of 70 and those with underlying health conditions are considered to be at increased risk of becoming more unwell if they do pick up the infection and the government has published a list of people deemed to be particularly 'vulnerable', for whom more stringent isolation at home for several months is being recommended. As of 30th March, all patients with Interstitial Lung Disease have been added to that group and you will be receiving a letter soon which gives more detailed advice about what this means for you. I am conscious that the constant stream of news and uncertainty is quite unsettling and can feel quite alarming.

Having a lung condition does not make you more likely to pick up the infection but does increase your risk of being more unwell if you do catch it. The government advice is intended to try to protect people at risk of severe illness and to reduce the overall numbers of people who become ill with the virus.

The coronaviruses are a large family of viruses, which cause respiratory illnesses ranging from the common cold to more severe illnesses like Middle Eastern Respiratory Syndrome (MERS) and Severe Acute Respiratory Syndrome (SARS). Scientists looking at the samples from people with the current coronavirus illness (referred to as Covid-19 – **Coronavirus Disease 2019**) have found that this virus is genetically similar to the first SARS illness and so have called the virus SARS Co-V-2.

The typical initial symptoms are of a flu-like illness with a new dry, continuous cough and high temperature. For most people the symptoms are mild and will go within a few days but it can result in a more severe illness, with a viral pneumonia and it is this that the isolation advised by the government hopes to avoid.

What is known about Covid-19 and this pandemic is evolving all the time and the advice has changed as the situation has progressed over the last couple of weeks. I have included some information in this newsletter but please do look at the official sites if you want information as these are updated regularly. The British Lung Foundation has some clear information and has links to Public Health England and other reliable sources.

We are having to work very differently at the hospital at the moment and are expecting to spend much more time caring for people admitted to the wards. Your routine appointments are likely to be replaced by a telephone call and we will do our best to continue to support you as best we can. At this stage, we are unable to say whether we can meet in June but will keep you posted. In the meantime, keep well and safe.

Best wishes, Sandra

Coronavirus (Covid-19)

The virus is carried on droplets from the respiratory tract and lands on surfaces within about 1.5-2 metres (about 5-6 foot) of anyone with the infection. It can live on those surfaces for up to 72 hours so it is easy for us to pick up the virus on our hands when we touch things in public spaces or around our home. We all touch our faces all the time, usually without even realising, increasing the risk that we will transfer the virus to our mouths and be infected. This is why there has been so much advice about handwashing – this virus is easily destroyed by thorough washing with soap and water so by washing your hands when you come into your home, after coughing or blowing your nose and after being in contact with others, the risk is reduced.

It is really important that we try to reduce the numbers of people getting infected with the virus so that there are less people getting seriously ill and to reduce the spread. This is why stricter social restrictions have been advised and you may have seen a number of terms have been used:

Social distancing – we are all advised now to avoid contact with those outside our immediate household, even family and friends who live elsewhere, and this is especially important for people over 70 or with long term health problems. Make plans to cope with this as it may be advised for some time.

- Avoid unnecessary trips away from home, including hospital appointments, unless urgent.
- If you do have to go out, keep at least 2 metres away from others.
- If you work, work from home or make alternative arrangements with your employer.
- Use telephone or online services to arrange shopping, prescriptions or to contact your GP or other care.
- Ask family and friends to help by picking up shopping or medicines and dropping them off for you.
- Ensure you have enough regular medication and take it as advised so that you keep as well as you can.
- Have contact numbers of friends and family handy in case you become unwell or need help.
- Ensure you have plans in place if you are caring for someone or have a carer, just in case one of you becomes unwell.

Self-isolation or household isolation – this applies to all of us now, not just those with symptoms of Covid-19. We should only go out for essential shopping, medical care or work that cannot be undertaken at home. As many people as can should work from home. We should not have visitors from outside our own households. Anyone developing a new continuous cough or a high temperature should stay at home for at least 7 days until the temperature settles. If there is anyone else in the household, they should also stay at home for at least 14 days or, if they also develop symptoms, for a further 7 days from when those symptoms start.

Social shielding – this term refers to the advice to those who are particularly at risk, who are advised to minimise all contact with others and stay at home at all times. Certain conditions have been named specifically but it makes sense for all with underlying health problems to follow this advice if at all possible. Carers providing essential daily support can continue to visit unless they get symptoms of Covid-19, when they must stay away. Anyone visiting should wash their hands thoroughly when they arrive.

Coping with social distancing/shielding:

- Regular contact with others is important so find ways of staying in touch by phone, post or using video calls via the internet (such as FaceTime or Skype).
- Try to keep mentally and physically fit – find some exercise you can do at home, spend time doing things you enjoy, try to eat healthily, make sure you drink plenty of fluids and avoid smoking (this increases your risk of infections and pneumonia).
- Try to get some sunlight and fresh air if you can – in the garden if you have one, or open a window.
- If you don't have anyone that can help with food or medication, register for support via <https://www.gov.uk/coronavirus-extremely-vulnerable>
- If you become unwell contact NHS 111 or your GP for advice.

Keeping Active - Pulmonary Rehabilitation

Paula Browne, Senior Respiratory Nurse Specialist, NNUH

Hello all, I'm sorry I wasn't able to meet you at the group meeting in March, but here is some information on the subject we would have covered.

Pulmonary Rehabilitation (PR) is made up of:

- a physical exercise programme, designed for people with lung conditions and tailored for you
- information on looking after your body and your lungs, and advice on managing your condition and your symptoms, including feeling short of breath

It's designed for people who are breathless and who feel they have lost the ability to be as active as they once were. A PR team will be made up of trained health care professionals such as physiotherapists, nurses and occupational therapists.

Courses are run in Norwich (the NNUH course is held at the Willow Centre, where the PF group meets) and across the county. A course usually lasts six to eight weeks, with each session lasting about two hours. Some courses have one session/week, others two sessions, and you are required to exercise most days. Completing a course of PR helps you to learn how to exercise safely and at the right level for you. It builds confidence and it is very helpful to meet others in a similar situation.

How will PR help?

'When I started the course, I could barely walk 500 metres before becoming too breathless to continue. By the end of six weeks, I could walk 1500 metres. It's not about getting better - it's about living better with my condition' *John*

PR can:

- improve your muscle strength so you can use the oxygen you breathe more efficiently
- help you cope better with feeling out of breath
- improve your fitness so you feel more confident to do things
- help you feel better mentally

PR helps you manage your condition and makes you feel better but is not a cure, so you are unlikely to see a difference in your breathing test results. What it can do, is help you make the most of the lung function that you have. There is evidence that it improves your ability to walk further, helps you feel less tired and breathless doing day-to-day activities and reduces your risk of ending up in hospital. The saying 'use it or lose it' is very true; we know when people get very breathless, their activity levels drop and their muscles weaken. There has been wide research into the effects of activity and exercise in people with lung conditions, which shows we can be less breathless if we are fitter and our muscles are stronger. You may be thinking you are too breathless to exercise, but the muscles just need to *be used* to get stronger, so the exercises are simple and repetitive, and as the muscles strengthen, the sensation of breathlessness lessens and we can walk more easily and manage day-to-day activities better.

What happens on a PR course?

A typical PR course will always start with an assessment of your health and abilities. Your PR team will ask questions to understand you and your body, so they can help you get the best out of the course.

Physical exercise

At each session, you will spend about half the time on physical exercise, designed to provide the right level of activity for you. You will get out of breath, but this is part of the therapy. You will always be monitored and won't be asked to do more than you can do safely.

Information and discussion

For the rest of the time, you'll learn about topics such as:

- why exercise is so important for people with lung conditions
- how to use breathing techniques during physical activity or when you feel anxious
- how to manage anxiety and low mood
- how to use your inhalers and other medicines
- how to eat healthily
- what to do when you're unwell

Of course, at the moment, all Pulmonary Rehabilitation classes have been cancelled, as we adhere to the Government advice on groups and social distancing.

However, it's a good time for you to start exercising in your home, and you don't need any special equipment! Walking is essential to get the leg muscles stronger, and an important message is that 'breathlessness will not harm you'. Walking around your home or in the garden is encouraged; you can stop and get your breath back whenever you need and then continue. Getting out of breath is a normal response to activity and exercise, and though it is unpleasant, it doesn't make your lung condition any worse. If you have oxygen at home, make sure you use it when exercising.

So, what else can we do at the moment? If you have access to the internet, there are You-Tube videos on Pulmonary Rehabilitation showing you exercises you can follow. The NNUH team made a video in 2012, filmed at the Community Hospital on Bowthorpe Road, which is called 'An introduction to Pulmonary Rehabilitation, NNUH' which gives a flavour of the programme we offer.

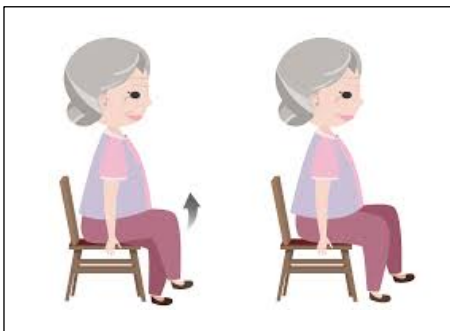
Any exercise that strengthens the big leg muscles is excellent; simple 'step ups', 'sit-to stand' and 'leg raises' can all be very effective. Start with small numbers of repetitions with rests in between; if you can only manage 2 or 3 that's fine, just increase as able. **The British Lung Foundation website has information on exercise and a booklet they will send free of charge, or you can phone 03000 030 555 and ask for the exercise DVD.**

If you are exercising at home, bear these points in mind:

- warm up before exercising and cool down afterwards
- carry your inhaler while exercising, if you use one
- wear loose, comfortable clothing and supportive, non-slip shoes
- wait for at least an hour after eating before exercising and drink plenty of water
- stop exercising if you get chest pains or tightness; if you feel dizzy or nauseous, clammy or cold; or if you feel increasingly wheezy or if your joints or muscles hurt.

Contact me on 01603 289779, or email paula.browne@nnuh.nhs.uk if you'd like to ask anything re exercising at home.

Paula Browne, Senior Respiratory Nurse Specialist, Respiratory Medicine, NNUH



Useful Information Sources

Websites:

The lung charities have some helpful information and resources; general information regarding living with lung conditions but also, at the moment, information about Coronavirus (Covid-19). Most also have helplines for further information and advice.

www.actionforpulmonaryfibrosis.org Action for Pulmonary Fibrosis **Advice Line 01223 785725**

www.pulmonaryfibrosistrust.org Pulmonary Fibrosis Trust **Advice Line 01543 442191**

www.blf.org.uk (British Lung Foundation) **Helpline 03000 030 555**

www.europeanlung.org/en (European Lung Foundation)

www.sarcoidosisuk.org (UK Sarcoidosis Charity)

Local contacts:

Sandra Olive, Consultant Nurse, Respiratory Medicine – 01603 289654

Oxygen/Pulmonary Rehabilitation Specialist Nurses & Breathe Easy Norwich – 01603 289779