



The Leeds
Teaching Hospitals
NHS Trust

The North of England Primary Ciliary Dyskinesia Service

Information for patients



Leeds Centre for
Cystic Fibrosis

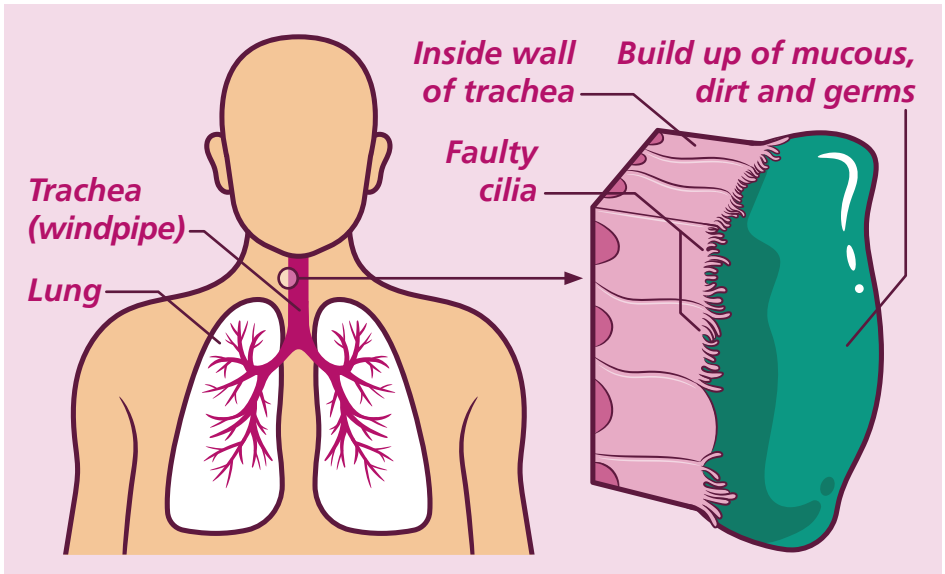


Welcome to the adult Primary Ciliary Dyskinesia (PCD) service based in Leeds. Whether you have just been diagnosed with PCD, or are moving over from the paediatric service, you probably have lots of questions.

What is Primary Ciliary Dyskinesia?

PCD is a rare, inherited disease that affects the microscopic hairs, known as cilia. Cilia help clear mucous, dirt and germs from lungs, nose and ears. These cells are also involved in the reproductive system and can affect a person's fertility.

In PCD, the cilia cells do not beat as they should and this can lead to repeated chest, ear or sinus infections. If left untreated, this can lead to lung damage known as *bronchiectasis*.



Some of the signs and symptoms include;



**Productive, wet cough
(even when well)**



Sinusitis (swelling of the small empty spaces behind cheekbones and forehead)



**Constant runny/
blocked nose**



**Shortness
of breath /
wheezing**



**Hearing
problems**

Some people with PCD have their heart on the right hand side of their chest, known as *dextrocardia*, or all their organs on the opposite side, known as *situs inversus*.

What is the treatment for PCD?

The aim of treatment is to maintain or improve lung function and minimise lung damage from infections. We do this by;

- **Airway clearance:**

Our physiotherapist will teach you techniques to help clear mucous from your airways. Regular airway clearance is the best way to reduce build-up of mucous and bacteria that can lead to chest infections.

- **Exercise:**

Regular exercise is good for overall health, but it also encourages deep breathing which can aid with clearing your chest.

- **Antibiotics:**

Your doctor may prescribe antibiotics when you have a chest infection, it is important you take them as prescribed. If you are very unwell these antibiotics may be prescribed as an injection and our nurses will support this treatment.

Occasionally, your doctor may prescribe you an antibiotic to take every day to prevent repeated infections.

- **Medications:**

As well as antibiotics, we may also prescribe other medications such as inhalers.

Many medications can have side effects and we will discuss this with you when you start a treatment. However, if you feel you are experiencing any side effects from your treatment do not hesitate to contact us on the number on the Useful Contacts page.

Managing treatment alongside a busy life can be difficult, but it is important to make time for your health.

Please talk to your healthcare professional if you feel you are struggling with any aspect of your treatment - *we are here to help!*

Outpatient Clinics.

Outpatient clinics are held at Seacroft hospital in Leeds with our specialist PCD team:



Seacroft Hospital
York Road
Leeds Teaching Hospitals
LS14 6UH

Buses travel frequently from Leeds city centre to Seacroft hospital, stopping on York Road.



The following buses travel between Leeds city centre and Seacroft hospital; **56, 64, 166, 402, 403, 770, 771, 843, 845**



Leeds train station is the closest train station to Seacroft hospital.



If you cannot attend please let us know as soon as possible using the phone number on the Useful Contacts page.

You may meet:

- **Specialist nurse**

nurses will check your blood pressure and oxygen levels. They will also take blood tests and arrange courses of antibiotics if needed.

- **Physiotherapist**

The physiotherapist will test your lung function using a machine known as a spirometer. They will also help plan your airway clearance management and assist you with any problems that arise.

- **Dietician**

Our specialist dietician will check your weight and discuss any problems relating to your oral intake and digestion system.

- **Doctors**

Clinics will be run by our respiratory consultants with a special interest in PCD and respiratory medicine. Doctors will plan your care with you and arrange your next appointment.

We have links with other specialities in the hospitals. If you need further treatment or referring to specialist services this will be discussed with you during your appointment.

Useful Contacts:

Clinical nurse specialists

Tel: 0113 2066816

Email: leedsth-tr.leedscfnurses@nhs.net

Seacroft Hospital outpatients department

Tel: 0113 2065402

Secretaries

Tel: 0113 2067170

Leeds Centre for Respiratory Medicine

Web: www.chestmedicine.co.uk/pcd

Further Support

PCD Family Support Group.

A registered charity supporting patients, families and their carers affected by PCD.

Web: www.pcdsupport.org.uk

Ciliopathy Alliance

A registered charity involved in raising awareness and research into diseases caused by ciliary dysfunction; including PCD.

Web: www.ciliopathyalliance.org



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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