

# Your self-management plan

## Primary ciliary dyskinesia (PCD)

### Welcome to the PCD service

This self-management plan has been designed to help you record details of your primary ciliary dyskinesia (PCD) treatment, action plan and key information about your health and wellbeing throughout the coming year.

Your hospital PCD team can use it to record information and there is space for you to record details of your symptoms, times you have been unwell or had infections, and medication that you have been prescribed. Keep this plan in a safe place and remember to bring it with you when you see your consultant, GP, specialist nurse or pharmacist.

### Your details

Name:

Date of birth:

Hospital/clinic

Hospital No.

NHS number

Plan created: .....

Name of healthcare professional : .....

Review due: .....

## Information for medical professionals

**Medical history:**

**Primary ciliary dyskinesia (PCD):**

**Current PCD medication:**

(Please note medications may change over the year - an up to date list is available from your GP):

**Allergies:**

**Summary of the previous 12 months:**

**Microbiology in the last 12 months:**

**Best lung function in the last 12 months:**

# Your recommended day to day chest / sinus treatment

Goal	Details
<p><b>Physio</b></p>	<ul style="list-style-type: none"> <li>• To continue with regular physio: ..... ..... ..... .....</li> <li>• If you are unwell, you should aim to: ..... ..... ..... .....</li> </ul>
<p><b>Medications</b></p>	<ul style="list-style-type: none"> <li>• Take your oral medication, nebulisers and inhalers as prescribed.</li> <li>• <b>Do not</b> allow medicines to run out.</li> <li>• Keep a rescue antibiotic course at home.</li> </ul>
<p><b>Exercise</b></p>	<p>..... ..... ..... .....</p>
<p><b>ENT</b></p>	<p>..... ..... ..... .....</p>
<p><b>Other</b></p>	<ul style="list-style-type: none"> <li>• Avoid smoking, ask for help from your practice nurse if needed.</li> <li>• Avoid visiting anyone who is unwell with a cold, Flu or chest infection.</li> <li>• Keep up to date with all recommended vaccinations including Covid-19.</li> </ul>

# My symptoms

When stable (not during a chest infection) - please tick those that apply

## Cough

- I normally cough most days of the week
- I normally cough one or two days of the week
- I normally cough a few days per month
- I normally cough only with chest infections

## Sputum

- I normally cough up sputum most days of the week
- I normally cough up sputum one or two days of the week
- I normally cough up sputum a few days per month
- I normally cough up sputum only with chest infections

## What colour is it?

- Clear
- White
- Light yellow or green
- Dark yellow or green

## How much do you cough day to day?

- 1 teaspoonful
- 1 tablespoonful
- Half a sputum pot
- \_\_\_\_ Sputum pot

## Is your sputum?

- Watery
- Sticky

## Breathlessness

- I normally get breathless walking around the home
- I normally get breathless walking outside on level ground
- I normally get breathless walking up a flight of stairs
- I normally get breathless playing sports
- I only get breathless with chest infections
- I never get breathless

## Other usual symptoms e.g. wheezing, tiredness, fatigue:

---

# Your action plan - what to do if you feel unwell

## If you feel unwell you should:

- Clear your chest more often, at least ... times daily
- Clear your sinuses more often, at least ... times daily
- Ensure you take all of your tablets, inhalers and nasal sprays at the correct dose
- Drink plenty of fluids

### Action

**Some colds get better without requiring antibiotics. If there is no change in the amount or colour of your sputum, do not start your antibiotics.**

## If you continue to feel unwell or:

- cough up more sputum, or sputum that is darker or thicker than usual, for more than 2 days
- have worsening breathlessness
- cough up streaks of blood
- have chest pain when you breath in

### Action

**Collect a sputum sample and send it in to University Hospital Southampton (UHS) or your local service and inform the PCD team. Start your standby antibiotics immediately without waiting for the sputum result. If no improvement within 72 hours of starting antibiotics contact the PCD team or your local respiratory team.**

## If you are:

- **confused or drowsy**
- **coughing up large amounts of blood (for example, \_\_\_\_\_)**
- **severely breathless**
- **breathless whilst talking**

### Action

- **Call the emergency GP or visit A&E (ring 999 if needed)**
- **Collect sputum sample if possible**
- **Start your standby antibiotics immediately.**
- **Update the PCD team and local service as soon as you can.**

# Chest infection symptoms to watch for

**Remember to look out for signs you may have a chest infection (you may have some or all of these)**

- you feeling generally unwell
- you are coughing up more sputum or sputum more sticky
- changes to the colour of your sputum (clear to yellow **or** light yellow to dark yellow/green)
- worsening breathlessness
- fever

## Antibiotics record

Use this table to keep a record of any antibiotics courses you have been prescribed this year.

Date	Name of antibiotic	Number of days taken	Oral or IV (intravenous)	Notes



# Travelling away from home

Record important information you may need when travelling away from home below:

Stand-by antibiotics	
Oral medications	
Inhalers and nebulised medications, if used	
Sinus rinse and nasal sprays	
Any equipment such as nebuliser or airway clearance devices, if used	
If going away for extended period of time (such as university, for example) please also:	<ul style="list-style-type: none"><li>• Take your home spirometer</li><li>• Register with a local GP to obtain your medications</li><li>• Update your health care teams with any change in contact details.</li></ul>



# Contacts

## Southampton PCD team

Telephone: **023 8120 6656** (Monday to Friday, 9am to 5pm)

Email: [adultpcdteam@uhs.nhs.uk](mailto:adultpcdteam@uhs.nhs.uk) (for non-urgent queries).

Your local respiratory team: \_\_\_\_\_

Your GP: \_\_\_\_\_

## If you need advice or have a question

If you need non-urgent advice before your next review contact the PCD team using the contact details above.

## Useful links

### PCD support UK

[www.pcdsupport.org.uk](http://www.pcdsupport.org.uk)

If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email **patientsupporthub@uhs.nhs.uk**

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **[www.uhs.nhs.uk/additionalsupport](http://www.uhs.nhs.uk/additionalsupport)**