



**Easy
Read**



**University Hospital
Southampton**

NHS Foundation Trust

Your PCD plan

This is your PCD plan. It helps you and your healthcare team look after your health.



This plan will help you:

- **Keep track of your care.**
- **Know what to do if you feel unwell.**
- **Share information with your doctors and nurses.**

This plan belongs to:

To be completed by a healthcare professional.

Full name:

Date of birth:

Hospital name:

Hospital number:

NHS number:

Date this plan was written:

Name of health professional who completed plan:

Date this plan should be reviewed:

About your health

To be completed by a healthcare professional.

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:


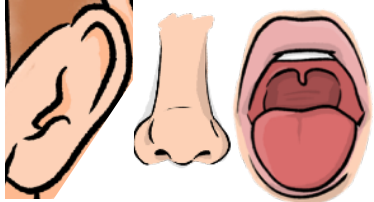
Summary of the previous 12 months:

Microbiology in the last 12 months:


Best lung function in the last 12 months:

Your goals for every day



To be completed by a healthcare professional.

Type of Goal		Details
Exercise		
Ear, Nose and Throat		
Other	<p>You should:</p> <ul style="list-style-type: none"> • Try not to smoke - you can ask for help to stop smoking at your doctor's. • Not visit anyone who has a cold, flu or a chest infection. • Have all the vaccinations your doctor recommends. <p>Vaccinations are injections or jabs that help to stop you from being ill with certain illnesses.</p>	Write any other goals here:

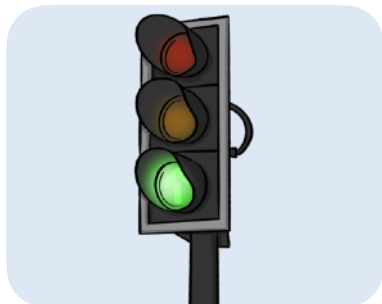
More goals for every day

Type of Goal		Details
<p>Physiotherapy</p> <p>Physiotherapy is treatment which helps you keep your lungs clear and keeps you healthy.</p>		<p>Try to do the things below:</p> <ul style="list-style-type: none"> • In the morning: • During the day: • In the evening: • If you are unwell you should:

More goals for every day

Type of Goal		Details
Your medicine		<p>You should:</p> <ul style="list-style-type: none"> ✓ Take all your medicine in the way you have been told to. ✓ Not run out of medicine. ✓ Keep antibiotics at home in case you need them. <p>Antibiotics are a kind of medicine that help if you have an infection.</p>
Other goals to do with medicine		

Your action plan

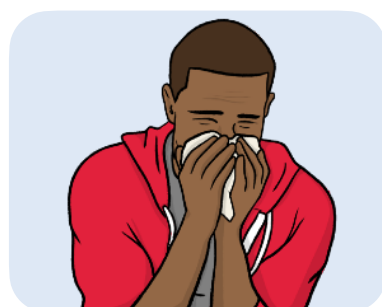


Green - you feel well

If you start to get ill, the treatments below may help you to get better:



- Clear your chest more often, at least times a day.



- Clear your sinuses more often, at least times a day.



- Make sure you take the right amount of all your medicines.



- Drink plenty of liquids.



Action

If you have done the treatments above and still feel ill after 2 days:



- Contact your PCD team.



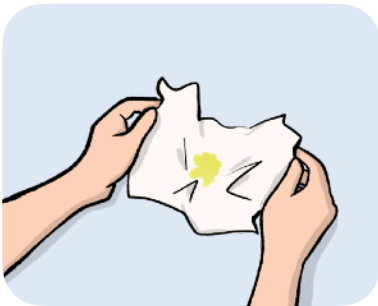
Action

- Follow the Amber action plan on page 10.



Amber - you feel unwell

You still feel ill even after doing more of your treatments. It might be that you:



- For more than 2 days, cough up more sputum, or sputum that is darker or thicker than usual.



- Find it more difficult to breathe.



- Cough up some blood.

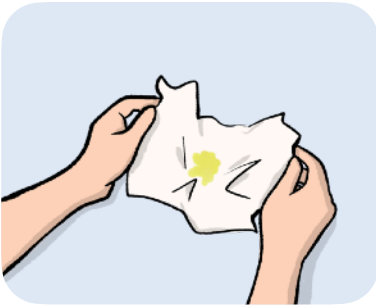


- Have chest pain when you breathe in.



Action

If you feel still feel ill or have any of the symptoms above, you should:



- Collect a sputum sample and send it to University Hospital Southampton (UHS), or your local service.



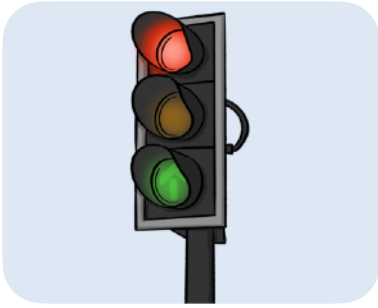
- Tell the PCD team.



- Start your standby antibiotics straight away.



If you do not start to feel better 3 days after you start taking antibiotics, you should contact the PCD team or your local respiratory team.



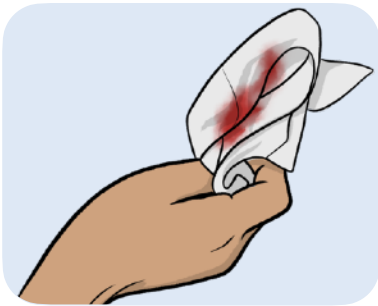
Red - you feel very unwell

You feel very unwell and need more help.

You might:



- Feel confused or sleepy.



- Cough up more than blood.



- Find it very hard to breathe.



- Find it hard to breathe when you are talking.

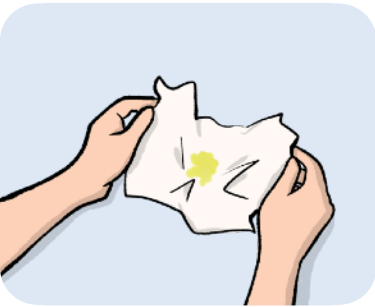


Action

You must:



- Call 111 or go straight to the emergency department (A&E). You might need to phone for an ambulance.



- Collect a sputum sample if you can.



- Take your standby antibiotics immediately.



- Tell the PCD team and local support team as soon as you can.

Your standby antibiotics



You might take antibiotics a few times during the year.



If you need to take your standby antibiotics please write it on this page and tell us at your next appointment.



Please bring the antibiotics you have been taking to your next appointment, even if the box is empty.

Date	Name of antibiotic	Number of days taken	Notes

For advice

If you need to talk to someone but it is not urgent, you can contact the Southampton PCD team by:



- Phone: 023 8120 6656
- Email: adultpcdteam@uhs.nhs.uk



You can contact us on Monday to Friday, between 9am and 5am.



You can write other useful phone numbers here:

Your local support team:

Your doctor:

Find out more



You can look at our website here:

www.uhs.nhs.uk



PCD Support UK have a website here:

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 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