

Patient guide: medication use

Information for patients

This leaflet answers common questions about medication use for patients. If you would like further information, or have any worries, please do not hesitate to ask your nurse or doctor.

About my condition

My diagnosis:

Regular treatment regime

Immunoglobulin replacement therapy

- Product:
- Quantity:
- Frequency:

Prophylactic (preventative) antibiotics

- Antibiotics:
- Frequency/dose:
- Duration: continuous

Breakthrough antibiotics

- Antibiotics:
- Frequency/dose:
- Duration: two weeks

Breakthrough chest infections

Signs and symptoms

- A more productive chest, i.e., increased levels of green coloured sputum
- A fever (increased temperature, over 38°C)
- Feeling cold and clammy
- Chills
- Previous cold that has developed into a chest infection.

What to do

1. Give a sputum sample to your GP or the Royal Free immunology team (preferably before starting the antibiotics), to test for infection.
2. Start breakthrough antibiotics for **two weeks**, finishing the full course (even if you feel better).
3. Stop taking prophylactic (preventative) antibiotics while taking breakthrough antibiotics.
4. If no improvement in three days, see your GP for assessment, and provide another sputum sample.
5. If the infection has not resolved after a two-week course of antibiotics, contact the Royal Free London immunology team.
6. Once the infection is treated, return to taking prophylactic (preventative) antibiotics, if you usually take these.

Important information about antibiotics

Always record the name of the antibiotic, dose, frequency and how you feel after taking it

Female patients

In the month following any change of antibiotics, your oral contraception might not be 100% effective and additional barrier methods (eg condom use) are recommended.

Your basic first aid kit

- Thermometer.
- Back-up courses of antibiotics.
- Paracetamol.
- Ibuprofen.
- Non-drowsy antihistamine (eg cetirizine).
- Rehydration sachets.
- Plasters.
- Anti-bacterial hand gel.
- Antiseptic cream or liquid (eg betadine).

The St John ambulance website provides more general, in-depth information for home first aid kits: www.sja.org.uk/get-advice/i-need-to-know/what-to-put-in-a-first-aid-kit/

Persistent diarrhoea

Signs and symptoms

Loose stools for more than seven days.

What to do

1. Contact the Royal Free London immunology team, who will send you two or three sample pots to collect stool samples to test for infection.
2. When these arrive, follow the instructions included and then return each pot containing samples in the individual bag provided, and write the date of collection on the pot.
3. The team will then let you know if a course of medication is required.

Make sure you drink plenty of fluids and taking rehydration sachets.

See your GP if you are unable to tolerate fluids, or if you have severe abdominal pain or blood in the stools.

Contact us

During working hours, the team are contactable by telephone: 020 7830 2141.

Opening times

The main unit opening times are Monday to Friday, 9am-5pm. Our administrator will be able to direct your query to the most appropriate member of the team. You may find it easier to email the department if your query is non-urgent: rf.clinicalimmunology@nhs.net.

Outside of working hours

Outside of working hours there is always a consultant available to speak to healthcare professionals (eg other doctors or nurses at an A&E, urgent care centre, local hospital, or GP practice). They can be contacted via the hospital switchboard: 020 7794 0500.

Your GP will remain your first point of contact. For out of hours medical support please call 111.

If you are too unwell to go to your GP, you should visit your nearest emergency department for review. Do not wait to speak to the immunology team before accessing medical help; we can always be contacted as soon as you are stable.

Change or cancel an immunoglobulin infusion appointment

To contact our nursing team about changing or cancelling an immunoglobulin infusion appointment please telephone 020 7794 0500 (switchboard) then extension 32232 or 32233.

Weekly clinic times

Wednesdays: 9am-12.30pm

General immunology (including primary and secondary immune deficiency), lung health and immunodeficiency, and chronic granulomatous disease (CGD) clinics.

Fridays: 9am-12.30pm

General immunology, young adult, bone marrow transplant, complement and joint immunology / hepatology clinics.

The infusion unit is open Tuesday to Thursday, 9am-5pm. Psychology clinics run on Tuesdays, Wednesdays, and Fridays.

If you require any further details, please ask a member of the team.

More information

For more information about the respiratory medicine service at the Royal Free London, please visit our website: www.royalfree.nhs.uk/services/respiratory-medicine

Your feedback

If you have any feedback on this leaflet or for a list of references for it, please email: rf-tr.communications@nhs.net

Alternative formats

This leaflet is also available in large print. If you need this leaflet in another format – for example Braille, a language other than English or audio – please speak to a member of staff.

© Royal Free London NHS Foundation Trust

Service: Pain management

Leaflet Reference: RFL746

Version number: 3

Approval date: May 2024

Review date: May 2027

www.royalfree.nhs.uk