

Patient guide: Medication use

Information for patients

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, ie increased levels of green coloured sputum
- a fever (increased temperature, over 38°C)
- feeling cold and clammy
- flu-like symptoms (eg chills, increased cough, sore throat)
- 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

Important information about antibiotics

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

Female patients please note: 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.

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.

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)

NHS Choices also provides more general, in-depth information for home first aid kits:

www.nhs.uk/chq/pages/990.aspx?CategoryID=72&SubCategoryID=725

Contacting the team

Opening times and contact details

The main unit opening times are Monday to Friday, 9am-5pm.

During working hours the team are contactable by phone:
020 7830 2141

You may find it easier to email the department if your query is non-urgent: rf.clinicalimmunology@nhs.net. We aim to respond to all emails within three working days.

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.

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, urticaria and angioedema, complement and viral skin infection (VSI) clinics.

Some additional clinics run several times a year on other days with specialists in liver, skin, gut or bone and joint problems.

The infusion unit is open Monday to Thursday, 8.30am-5pm. We also run a late (evening) infusion clinic once a month.

Psychology clinics run on Tuesdays, Wednesdays and occasional Fridays.

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

The team

Nurses

- Andrew Symes, clinical nurse specialist
- Sarita Workman, research sister
- Mojama Abdulai, immunology junior sister
- Aveen Murphy, infusion nurse specialist
- Irene Wahlberg, immunology junior sister

Consultants

- Dr. David Lowe, consultant
- Dr. Siobhan Burns, consultant
- Dr. Jovanka King, consultant
- Dr. Suranjith Seneviratne, consultant

Psychologist

- Dr. Mari Campbell, consultant clinical psychologist
- Rupert Goodman, assistant psychologist

Other team members

- Fernando Moreira, research assistant
- Arturo Mandapat, assistant practitioner
- Johanna Heinke, pathway co-ordinator

More information

For more information about the immunology department at the Royal Free London visit our website:

www.royalfree.nhs.uk/services/services-a-z/immunology

Your feedback

If you have any feedback on this leaflet or for a list of references for it, please email: rf.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.

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