Welcome to the Complex Asthma Service at GOSH

Information for families

Great Ormond Street Hospital for Children NHS Foundation Trust
This information sheet from Great Ormond Street Hospital (GOSH) explains about the Complex Asthma Service, who you will meet and what to expect when your child visits us for assessment and treatment.

The Complex Asthma Service at GOSH offers assessment, advice and support for children with difficult to manage asthma symptoms. Most children using our service come from the North London area although some come from further away. Most will already have seen asthma specialists at their local hospital but need more specialist assessment to manage their symptoms.

The specialist team at GOSH includes an Asthma Consultant (specialist doctor) and a Clinical Nurse Specialist. We are supported by colleagues from other specialties at GOSH including lung function, psychology, dietetics, ear nose and throat, speech and language therapy and physiotherapy.

Within GOSH, we have a wide range of imaging and diagnostic services for children and young people on one site. We are also linked to national and international research centres so we may tell you about current research projects if you want to take part.
What will our first clinic appointment involve?

As the GOSH service is a specialist one, your first clinic appointment may be a bit different to ones you have had elsewhere. Your first visit will usually be longer—often lasting around 45 minutes. Sometimes our appointments run over—if it takes longer than planned to explain a diagnosis or treatment to another family, this can have a knock-on effect on the rest of the clinic. Please allow plenty of time on either side of the appointment. We will do what we can to keep to time and try to keep you informed about any delays.

Our main aim for the first appointment is to find out more about your child’s asthma—we will ask lots of questions including:

■ How does asthma affect them?
■ When did you first notice it?
■ To what degree does their asthma stop them doing day to day activities?
■ Does anything specific make it worse or better?
■ Does your child have any other symptoms that might be linked?
■ What tests has your child had at other centres?
■ What treatments have they tried already?
■ How well did they work?
It can help us if you think about this before the appointment, perhaps making some brief notes of what happened and when. You can also bring along any reports or records you have from other centres, although we may have received some of this information with your referral. Please bring in all your child’s medications including spacer devices – as part of the assessment we will go through these and check how your child is using them. If your child is taking medication for any other problems, including ones bought from a chemist or any alternative/complementary medicines, please bring these with you as well.

If your child is three years old or more, we usually try to carry out lung function tests in our specialised laboratory during each appointment. Your appointment letter will give more information about this – testing usually takes 45 minutes or so at the first visit, but will take less time at future appointments. More information about lung function testing is available on our website. We will also ask you to complete some questionnaires with your child to find out how your child deals with their asthma symptoms and their severity. These give us a useful baseline so we can repeat them later on to see whether treatment is making them better. Sometimes we ask children to have a chest x-ray or blood tests.
Once we have heard your child’s asthma story, we will be able to make a plan for any other tests or referrals to other members of the team. We do not always make changes to your child’s treatment at this first appointment. When your child has had all the tests requested, the entire Complex Asthma team will discuss them to decide which treatment(s) to recommend. We will write to the doctor who referred you and to your family doctor (GP), outlining our recommendations and future plans. We will send you a copy too – if you would like to discuss what the letter says, please contact the GOSH team. We will contact you if there is anything you need to know about your child’s treatment before the next appointment.
The next appointment and afterwards

In our letter, we will let you know if and when we would like to see your child again. We tend to see children and young people every three to four months, depending on their planned treatment. Follow-up appointments are often shorter than the initial one – we have already collected a lot of information about your child and their asthma, so the aim of these appointments is to monitor their breathing, again using symptom questionnaires, lung function and other tests.

There are a number of options for treatment, including changing the way your child takes their medication, trying new medications or making lifestyle changes. We will discuss all the options relevant to your child with you and your child so that we can reach a decision together. We have several information sheets both about asthma in general and specific treatment options – please ask us for a copy.
As your child grows older

GOSH is a hospital for children and young people so as your child grows older and becomes independent, they will want to transfer to an adult team. We call this ‘transition to adult care’, which we view as:

the purposeful, planned process of preparing young people and their families or carers for, and moving them from, child-centred healthcare to adolescent or adult oriented healthcare.

The transition to adult care process aims to:

- Support teenagers to develop skills which allow them to manage their health more independently
- Support parents in helping their teenager to achieve this to the best of their ability
- Prepare young people and their families for transfer from child-centred healthcare to adult healthcare

One of the Complex Asthma team will be your named worker who will help coordinate your child’s care and offer support before, during and after transition to adult care. We will work with your child to help them learn about their condition and start seeing clinical staff on their own without you present. We realise that this can be a worrying time for you as parents so we also help you to step away from close supervision and allow your child to manage their own health.

Young people attending the Complex Asthma Service at GOSH who are likely to need specialist asthma care as adults will be offered transfer to The Barts Health Difficult Asthma service, held a short bus ride away from GOSH. We hold special joint clinics at GOSH which are attended by members of the Barts team so you can get to know each other in advance of your child’s transfer at 16 to 18 years old.
Further information and support

You can contact the GOSH Complex Asthma team with any questions or queries by emailing Gos-tr.ComplexAsthma@nhs.net or by telephoning 020 7405 9200 and asking for extension 5914. We aim to check the email at least twice a week.

If you are worried that your child is acutely unwell or having an asthma attack, you should see your family doctor (GP) or go to your nearest Accident and Emergency department as you would usually. The doctors there will let us know that your child is unwell and can ask for our advice if required.

The Complex Asthma team uses information provided by Asthma UK – you may wish to visit their website at www.asthma.org.uk/advice or call their helpline staffed by asthma specialists on 0300 222 5800 (Monday to Friday from 9am to 5pm).