



Cystic Fibrosis Annual Review

Why do we do annual reviews?

Annual reviews are undertaken on a yearly basis to assess your child's overall health and progress in relation to cystic fibrosis (CF). The results obtained enable us to put together a clear management plan for the next 12 months and to address any areas of concern identified during the review.

The annual review process is divided into two parts. The first is the assessment day which involves a combination of various tests and the clinical assessment of your child's current health status by the CF team. The day is designed to provide more time with members of the CF Team than is usually available in the CF clinic. This allows more detailed discussion of any relevant issues. The results and information obtained are then collated and discussed during a CF team meeting so that a plan of care can be made.

Four to six weeks following the assessment day, you will be sent an annual review appointment. This will take place during a normal Tuesday afternoon CF clinic but will be a slightly longer appointment than usual and will always be with a CF consultant.

Your input to the annual review is vital and you will, of course, have the opportunity to ask questions, find out more about new therapies or discuss any problems you may have.

Assessment day

Who will you see on the assessment day?

- A CF doctor (fellow or registrar) to run through the events of the previous 12 months and assess your child's current clinical status
- CF Nurse Specialist
- CF Physiotherapist
- CF Dietitian
- CF Psychologist
- CF Pharmacist

What tests will be done on the assessment day?

- **Lung function tests** – These are breathing tests which vary slightly according to age but are generally not undertaken until around the age of four to five years. Some children may be involved in our infant lung function or pre-school testing programme and if this is the case, the appropriate team will contact you separately to coordinate the appointment with the assessment day.
- **X-rays** – A single chest x-ray will be undertaken. Some children also require further x-ray investigations such as an ultrasound scan or CT scan - we will let you know if and when this is necessary. Routine bone scans are undertaken in all children from the age of 10 years.



■ **Blood tests** – A variety of blood tests are carried out to help us put together an overall picture of your child's current health status. This is often the most stressful part of the day and so we try to get it done as early as possible. Creams and cold sprays are available as required and our senior health care assistant will discuss the options with you.

■ **Exercise test** – The physiotherapist will undertake an exercise test as part of the physiotherapy assessment. This is usually a step test and it is therefore advisable for your child to wear loose comfortable clothing and trainers.

Where do we have to go and when?

We will send you a timetable of your assessment day which gives the details of the time and location of each appointment. It is a very busy schedule and it is very important that you arrive on time for your first appointment; otherwise all the other timings get delayed and may mean that you miss important parts of the assessment.

What information do we need to bring on the assessment day?

We will also send you a food diary which should be filled out over three days so that we can get an overview of your child's nutritional intake. Please bring the completed diary with you on the day of your review.

Please also remember to bring your child's physiotherapy airway clearance device you if you have one (such as PEP mask/ Acapella® Choice).

Please bring all your child's current medications (except those that need to be kept in the fridge) so that we can go through them.

In addition, we need to assess how your child has been during the previous year and will be asking several questions during the assessment. It may be helpful to think about these beforehand:

- How well has your child been during the past year? Has it been a good or a bad year with regard to cystic fibrosis?
- Has your child been admitted to hospital during the past year? If so when, for how long and why?
- Has he or she needed any additional courses of antibiotics? If yes, which ones were they, when and why?
- How much school has your child missed during the past year and why?
- Any concerns at all that you have regarding your child's health

You may also have questions to ask us – feel free to write these down to ask on the day.



Annual review appointment

This appointment takes place at GOSH about four to six weeks after the assessment day during a Tuesday afternoon CF clinic. It will be a longer appointment than usual and is the time when a CF Consultant will discuss all the various results and information collected on the assessment day.

A careful plan of management for the following year will be made and you will have a further opportunity to ask questions or raise any issues of concern.

This is probably the most helpful part of the review for both parents/carers to attend (as the assessment day is purely for gathering the appropriate information needed for this formal review appointment). All members of the CF team will be in clinic but the main focus will be the review with the consultant.

Following the appointment you will receive a written summary of the annual review results, discussions and management plan.

If you have any questions about the assessment day and/or annual review appointment, please telephone the CF Office on 020 7762 6714 or email cysticfibrosisunit.query@gosh.nhs.uk

Notes

Compiled by the Cystic Fibrosis Team
in collaboration with the Child and Family Information Group

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