

Paediatrics - Clinic 6

Cystic fibrosis – annual review

Information for parents

What is an annual review?

This is a detailed assessment of your child's condition and treatment, which is done once a year to review treatments and progress, to screen for possible complications, and to make plans for the forthcoming year. In the East Anglian Regional CF Network, it is normal practice to perform annual review for all CF patients at the CF Centre.

You and your child will be seen by all the members of the cystic fibrosis (CF) team, and investigations such as blood tests and x-rays will be performed. It has been found that most families prefer to have all the tests and appointments completed on one day, although this can make the annual review day seem quite long.

Every effort is made to keep appointments on schedule, with minimum delay, and for this reason we ask that you try to arrive on time. Please bring some toys and favourite activities to help to keep your child occupied.

This leaflet gives information regarding each of the appointments you will have at the annual review.

Nurse review

The specialist nurses will discuss with you general issues, such as education, social circumstances, benefits, and equipment. They will also co-ordinate the day, organise the blood tests and glucose tolerance test, and feed back to you any results which may need urgent action, before the report comes out (usually 6-8 weeks after the appointment).

Dietetic review

This is a detailed assessment of your child's nutritional status. One of the Dietitians will assess your child's:

- Dietary intake: looking at all nutrients, and comparing them with age appropriate requirements. In order for this to be of most benefit and accuracy please ensure that you return your food diary before the annual review appointment so that the results can be shared with you in the consultation.
- Growth and weight gain over the last 12 months.
- Vitamin supplements, adherence and knowledge. Doses may be altered when the vitamin blood levels become available, usually 4-6 weeks after your appointment.
- Enzyme dosage in relation to food intake, dosage for weight, adherence, knowledge and stool symptoms.

Please make sure that you have completed and returned your child's food diary before the annual review appointment. There will be plenty of time for you and your child to ask any questions and discuss any changes or aims you have for the coming year.

Physiotherapy review

During this review, your child's physiotherapy treatment methods are checked, progressed and/or modified; therefore any devices used for airway clearance should be brought to the annual review. Any issues or problems can be discussed at this time, to find ways of making physiotherapy easier to achieve, as it is expected that every child will go through stages of not engaging with their physiotherapy sessions!

Other areas that are checked in this session are:

- Posture – an assessment is done, and exercises and advice are given as necessary.
- Stress incontinence – if your child is experiencing this problem, exercises and advice are given. Preventative advice will be given to adolescents.
- Exercise tolerance – this is performed in the lung function laboratory and the choice of test is dependent on the age of your child and their general fitness, but exercise testing is not usually done under eight years of age. Please bring trainers for the exercise test.
- Cough swab/ sputum specimen is taken (preferably a sputum sample at annual review).

Psychology review

One of our psychologists will meet with all families as part of their annual review. Generally, the psychologist will see the child with their parents and will also see the child on their own once they are of school age and feel confident to speak to the psychologist. The psychologist will be guided by you in this matter.

You will be asked about your child's general wellbeing during the year, including CF treatments, school and any other issues that you would like to discuss.

Pharmacist review

The pharmacist will take a detailed list of all the medications your child is taking; and then review all the medicines and doses to ensure they are optimised for your child.

There will be an opportunity to discuss any difficulties or problems regarding your child's medicines, including side-effects or supply issues.

Please make sure you bring in a list of all the medications your child is taking.

Blood tests

All children will have blood tests taken to assess various aspects of their cystic fibrosis disease, including vitamin levels, liver function and immune status. Local anaesthetic cream or cold spray, and the play specialist, will help to try to make this procedure as quick and painless as possible.

Oral glucose tolerance test (OGTT)

The OGTT is performed annually to check for diabetes in children **over the age of 10 years**. A cannula may be inserted into a vein (or Portacath accessed) to take blood, and then your child will be asked to have a specific amount of a sugary drink. Bloods are then taken again after one and two hours, and then the cannula will be removed. Alternatively, instead of a cannula, we can do separate blood tests with a 'butterfly' needle. Your child must have nothing to eat from midnight on the day of the test, but may continue to drink plain water. When the final blood test is done after two hours, your child may eat and drink normally again.

Lung function

Formal lung function tests are performed, usually after the age of six years (depending on your child's ability), by the lung function laboratory in clinic 2a. They are similar to the lung function tests performed in clinic but also include some additional breathing tests, and sometimes an exercise test.

If we do not feel that your child is quite ready for the laboratory this year, we will do lung function in clinic as usual.

Abdominal ultrasound scan

The ultrasound scan will assess your child's liver, spleen, kidneys, pancreas and gut wall thickness.

Chest x-ray

The chest x-ray will assess your child's lungs for evidence of infection or damage; and will be compared to films from previous years.

DEXA scan

It is recommended that all children with cystic fibrosis have a bone density scan (DEXA scan) **from 10 years of age**, either annually or every two years, depending on the results. The DEXA scan is an x-ray of the spine which tells us how dense and strong your child's bones are; less dense bones can be more brittle in adulthood. The dietitian will inform you of the results usually within two months of the test. Should you have any questions about this please do not hesitate to contact your dietitian.

Medical review

In addition to an assessment of your child's current health, the medical review is also a general overview of your child's health and care over the past year. All medication and treatments will be reviewed and any necessary changes made to optimise CF treatment for your child.

What happens next?

The results are collected together and a report will be sent to you and to your GP. Some results can take up to six weeks to come through. It is important to remember that the report is a medical document and as such, may contain terms you may not fully

understand. The report should be discussed with you and your child at your next clinic appointment about two months after the annual review. Any results requiring action before this time will be discussed with you by the cystic fibrosis nurses.

If you have a shared care arrangement with another hospital, then your local cystic fibrosis paediatrician will also receive a copy of the annual review.

The cystic fibrosis team at Addenbrooke's

The members of the cystic fibrosis team may be contacted during working hours, Monday to Friday, via the cystic fibrosis consultants' secretaries on 01223 216020 or 01223 256291, or the cystic fibrosis nurse specialists on 01223 216277.

The team comprises:

- Dr Donna McShane - Lead Consultant
- Dr Wanda Kozłowska – Consultant
- Dr Louise Selby - Consultant
- Stephanie Aldridge - Paediatric Pharmacist
- Amy Shayle/Philippa Lewington - Paediatric Psychologists
- Stephanie Aldridge - Paediatric Pharmacist
- Helen Milroy/ Celine Prescott - Cystic Fibrosis Dietitians
- Monica Musgrave/ Laura Lowndes/ Kieren Lock - Cystic Fibrosis Physiotherapists
- Caroline Seward/ Mel Murray/Scill Gompelman - Cystic Fibrosis Nurse Specialists
- Tracey Nunn/ Manuela Antunes - Secretaries
- Vinod Thoppil - Database Manager

Checklist for CF Annual Review

Date:

Time:

- Please send back your food diary
- No vitamins the night before or morning of annual review
- If you are having a glucose tolerance test – no breakfast!
- Bring a list of your medications
- Bring any physio equipment with you
- If you have an iNeb please bring it for downloading
- Bring nebuliser for service if needed (Addenbrooke's equipment only)
- Bring trainers for exercise test
- Bring something to do



We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site. For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats:



If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team: docteam@addenbrookes.nhs.uk.



Please note: We do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.

Document history

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