

Cystic Fibrosis Annual Review

INFORMATION FOR PARENTS



WHAT IS AN ANNUAL REVIEW?

Your Cystic Fibrosis (CF) annual review is a detailed assessment of your child's condition and current therapies. This enables us to assess changes over the last year, identify where treatments can be improved, and produce a plan for the following year.

The CF nurse will call prior to your annual review appointment to ask you about the past year and your hopes/focus for the year going forward.

ANNUAL REVIEW APPOINTMENT

The dietician will discuss food and drink intake with you, assess calcium intake and review vitamins, Creon dose and bowel function.

The physiotherapist will discuss airway clearance technique, exercise, posture and incontinence issues. Young people over the age of seven will undertake a physiotherapy exercise test.

The CF nurse will discuss all aspects of care, emotional wellbeing, educational needs and relationships.

The clinical psychologist will give you an opportunity to reflect on the past year, as well as discussing coping, emotions, and behaviour.

The physiologist will check lung function using spirometry.

The pharmacist will review medications and make any changes as necessary.

ANNUAL REVIEW TESTS CARRIED OUT IN ADVANCE OF APPOINTMENT

Blood tests. An oral glucose tolerance test will also be taken if over 10 years of age. An oral glucose tolerance is taken over two hours to assess how your body deals with glucose. A cannula will be put into the vein and baseline bloods taken. Following this a glucose drink will be given and bloods will be taken from the cannula at regular intervals to assess glucose levels.

Liver ultrasound scan and chest x-ray.

Sputum specimen. Induced sputum if over 5 years of age (the patient needs to inhale nebulised Hypertonic Saline solution which allows expectoration of secretions).

Dietetic review

Physiotherapy review (including exercise test if over 7 years of age).

INVESTIGATION	REASON	FREQUENCY
CHEST X-RAY	To check the health of your lungs.	ANNUALLY
ABDOMINAL ULTRASOUND SCAN	To screen for CF related liver disease	ANNUALLY
ORAL GLUCOSE TOLERANCE TEST	To screen for CF related diabetes	ANNUALLY - if over 10
BLOOD TESTS	To monitor CF and medication effects	ANNUALLY
SPUTUM/COUGH SWAB	To check what is growing in your lungs	EVERY VISIT
EXERCISE ASSESSMENT	Assessment of exercise capability	ANNUALLY - if over 7
DEXA SCAN	X-ray which measures bone density	EVERY 3 YEARS - if over 10. Annually if bone density is low
AUDIOLOGY	Hearing test	IF ON AMINOGLYCOSIDES

We understand that some of the tests carried out can be distressing for some children.

FURTHER INFORMATION

The What? Why? Children in Hospital website has information and videos that include children talking about certain tests; you might find it helpful to look at these with your child.

www.whatwhychildreninhospital.org.uk

There is also a free app which is available from the Appstore and Google Play called HospiChill available on iphone and android. This helps you/your child prepare for hospital appointments and procedures with tips and tools to help with relaxation. There is also a booklet which is an alternative to the app called The Hospital Passport. If you think that your child would prefer the booklet ask a member of the team about receiving a copy.



www.careopinion.org.uk

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