Cystic Fibrosis Annual Review

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CF Trust Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK 2011, 2nd edition:

“*The annual review is a detailed assessment of every aspect of the patient’s condition and therapies, to assess changes over the last year, identify where treatments can be improved, and produce a management programme for the following year.*”

For all patients with CF who are under the care of the Royal Alexandra Children’s Hospital, Brighton as the CF Centre: The Annual Review takes place as near as possible to the child’s birthday.

5 components:
- Home visit
- Hospital Visit
- Data correlation and referral
- Pre-annual review clinic multi-disciplinary team meeting
- Annual Review multi-disciplinary clinic.

1. **Home visit**
   Undertaken by CF Nurse Specialist (Network/Centre) 6-8 weeks before clinic appointment.
   - Annual review questionnaire (holistic review including lifestyle, treatment adherence, school, education and understanding of CF)
   - Psychology screening questionnaire
   - Transition – ‘Ready, Steady, Go!’ assessment (starting at age 11-12 yrs.)
   - Specific mention when appropriate of puberty, fertility, transition, pregnancy, transplantation
   - Life milestone planning (starting nursery, school, university)
   - Treatment equipment review (nebuliser/inhaler techniques)
   - 3 Day Food Diary
   - Stool and Urine sample pots (Stool sample to coincide with timings of food diary whenever possible)
   - Preparation for blood tests.
   - Preparation for Modified Glucose Tolerance Test (aged 10 and over – CFRD screening guidelines)
2. Hospital Visit

With CF Nurse Specialist to coordinate approx. 4 weeks before clinic appointment.

- Blood tests via portacath by CF Nurse Specialist or cannula by Phlebotomist:
  - FBC
  - U and E
  - Creatinine
  - LFT’s
  - IgE,
  - Vitamin A, E and D
  - Zinc
  - HBA1C,
  - Random glucose or modified GTT (over 10)
  - INR (with CF Liver disease)
  - Ferritin

- Spirometry & Body Plethysmography (pre and 15 minutes post bronchodilator)
- Chest X-Ray
- Food diary collection for CF dietitian
- Stool Sample for Microscopy for fat globules
- Urine Sample for glucose urinalysis (in OPD)
- Urine Sample for urinary sodium & electrolytes (lab)

- CF Physiotherapist review:
  - Modified VO2 Max exercise test – age appropriate
  - Physiotherapy review of airway clearance techniques and equipment
  - Discuss goal orientated plans for the year ahead
  - Sputum sample/Cough Swab (Sputum sample sent for Non-tuberculous mycobacterium)
  - Assessment of posture and review of continence issues

3. Prior to Annual review clinic

- Audiology (if received one or more aminoglycoside courses in previous year)
- Bone densitometry (DXA scans) 2 yearly over the age of 10yrs (annually if abnormal).
- Liver Ultrasound scan 2 yearly over the age of 5yrs (annually if abnormal).
- Data correlation and entry to local CF database
- Referral as necessary to Social care agencies
- Continuous Glucose monitoring if indicated from screening or as requested by Endocrine team (See CFRD guidelines)
- Update and collate information from other specialties: Liver (Kings), Gastro, CAMHS
4. **Pre-Annual Review Multidisciplinary team meeting** (Network & Centre teams)

- Review of issues raised at home visit
- Review of respiratory status for the year
- Review of investigations
- Chest x-ray review
- Assessment of nutritional status and evidence of malabsorption, following food diary analysis and enzyme use, nutritional support and vitamin supplementation
- Review of Psychology screening tool & discussion of psychosocial factors in patients care if significant
- Specialist pharmacist review and discussion of all medication, both prescribed and non-prescribed and review adequacy of supply arrangements.

5. **Annual Review Multidisciplinary Clinic** (Network & Centre teams)

(To be seen by CF Consultant, CF Nurse Specialist, CF Dietitian, CF Physiotherapist, CF Psychologist)

- Pulse Oximetry
- Height & Weight measurement
- Growth Velocity recording and assessment
- Detailed assessment of the patient’s condition, therapies, changes over the last year, treatment improvements, lifestyle and education issues
- Download of digital nebuliser data, monitoring treatment adherence, technique and efficacy (as appropriate)
- A management plan should be discussed with the patient / carers and agreed
- A report should be written by a consultant once all results are available, and sent to the GP, shared care consultant and patient / carers.
- CFRD Patients – Annual review with Endocrine team and incorporated into CF Annual review management plan
- UK CF Registry (PORT CF) entry