**Monitoring children with cystic fibrosis**

At Perth Children’s Hospital, our specialised cystic fibrosis team will regularly monitor the progress of cystic fibrosis management and aim to optimise care. Each child’s situation is unique, and the information provided here is generic. We encourage you to discuss any questions relating any of the investigations and assessments with our CF nurses and/or your child’s doctor.

### Routine Reviews

Regular reviews are crucial for timely detection and prevention of complications. Routine reviews are conducted 3-monthly, but more frequent, tailored reviews may be needed at times for example, shortly after diagnosis or if unwell.

#### Clinical Assessment
- Multidisciplinary team review
- Clinical history and physical examination
- Medication adherence
- Measurement of weight and height

#### Lung Function Tests
- For children 6 years and older
  - FEV1: forced expiratory volume in 1 sec
  - FVC: forced vital capacity

#### Sputum sample
- If the child is old enough to expectorate
- For microbiological investigations
- With or without physiotherapy assistance

### Annual reviews

A review of all investigations and assessments made by the multidisciplinary team in the past 12 months to understand the current status and progress, and to devise a management plan for the next 12 months. In addition to routine assessments, annual review tests may include the following:

#### Blood tests
- Full blood count
- Kidney function
- Vitamins A, D, E
- Clotting tests
- Liver function
- Iron studies
- Allergy tests - inc. for the mould, Aspergillus

#### Dietetics
- Nutritional assessment, salt requirement
- Vitamin deficiencies
- Monitor for pancreatic insufficiency and bowel activity

#### Physiotherapy
- Airway clearance routines and equipment
- Musculoskeletal assessment and nebuliser use
- Exercise and physical activity
- Monitor for continence and bone health

#### Screening for other complications
- Be aware of other potential complications of CF including:
  - Bowel obstruction
  - Nasal polyps and sinusitis

#### Gastroenterology
- Clinical assessment by gastroenterology doctors.
- Monitor liver and bowel disease.

#### Psychological review
- General mental health and wellbeing
- Quality of life
- Adherence to treatment
- Psychosocial problems

#### Chest CT scan
- Low dose radiation CT scan
- Monitor chronic respiratory disease

#### Bronchoscopy
- For children aged <6 years
- Separate Health Facts sheet available.

#### Endocrinology
- Screening for children aged ≥10 years
- Glucose tolerance test screening for CF-related diabetes.
- Not always done annually

#### Musculoskeletal
- Screening for children aged ≥10 years
- Bone density scan (DEXA scan)
- Not always done annually
- Monitor for muscle pains and arthralgia

#### Adolescence
- For children aged ≥13 years
- Transition readiness checklist
For more information

- About the bronchoscopy procedure – Health Fact sheet (PDF)
- About the Cystic Fibrosis service at Perth Children’s Hospital