Perth Children's Hospital

Health Facts

# 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 1sec
**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

### Physiotherapy

Airway clearance routines and equipment
Musculoskeletal assessment
Inhalation therapy 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

### Dietetics

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

### 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

### Adolescence

For children aged ≥13 years
Transition readiness checklist

### 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

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## For more information

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

Government of Western Australia
Child and Adolescent Health Service

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