



The roles of the individual Cystic Fibrosis team members are outlined and an overview of Cystic Fibrosis care centres is provided, along with what you should expect to happen at clinic appointments and annual assessments.

The CF Team

CF Centres are located within hospitals in Ireland providing out-patient; daycare and in-patient services when required. There are two types of CF Centre. The 'Specialised CF Centres' are located in our major cities. A smaller number of 'Shared Care Centres' are located in smaller regional hospitals which work in partnership with one or more designated larger Specialised Centres when required.

A multidisciplinary team should consist of a CF Consultant, CF Nurse, CF Physiotherapist, Dietitian, Social Worker and Psychologist. Each of these members plays an important role in ensuring the best possible health outcome for your child. Here is a little more information about the roles of each of these multidisciplinary team members:

CF Consultant and Doctors

The CF Consultant leads the MDT, will make all medical decisions regarding prescription of medications and will be responsible for the overall care of your child. The CF Consultant is also often involved in CF related research.

CF Nurse

The CF Clinical Nurse Specialist (CNS) has an important role of the MDT by linking the CF team, the people with CF and their families. Education and training forms a large part of the role of the CF CNS, especially at diagnosis. The CF Nurse will be involved in decision making and monitoring of your child's care, and provide support and advice to you about the treatment and management of CF.

The CF CNS will provide information on how to care for your child, how to administer medications, advice on commencing new treatments, nebulisers, home intravenous antibiotics etc.

Patient advocacy is also an important part of the nurses role; they may act as a liaison between you and community services. The specialist nurses can often be your first point of contact if you have any concerns or worries.

CF Physiotherapist

The CF Physiotherapist Specialist will instruct you on how best to carry out airway clearance techniques on your child and will advise and provide training to you on how to use inhalation devices (e.g., nebulisers). They may also advise you on physical activity/exercise programs for your child. Their aim will be to keep your baby's lungs clear of secre-



A multidisciplinary team (MDT) of healthcare professionals will hold ultimate responsibility for the care of your child.

tions in order to lessen the risk of infection. An individualised physiotherapy plan will be developed for your child that will be continuously modified as age, needs and circumstances change.

CF Dietitian

The CF Dietitian will ultimately advise and educate you about the principles of nutritional management in CF including why and when your baby will need to take enzymes and vitamin supplements. The CF Dietitian Specialist will also ensure your baby is eating the right foods to gain and maintain weight. They will develop a nutritional care plan to best suit your baby's needs.

Social Worker

The medical social worker has specialised knowledge of key support services available for your family, and will provide practical and emotional support when needed. The Social Worker will advise you about benefits and allowances and will liaise with local community support services/agencies where necessary.

Psychologist

If you are experiencing any anxiety or emotional difficulties as a result of your baby being diagnosed with CF, the clinical psychologist will be there to support you and help you to better cope with these feelings.

The CF multidisciplinary team will meet regularly to discuss the care of your child to ensure best possible outcomes for treatment and management of the disease.



Hospitals that Care for Children and Adults with Cystic Fibrosis

A specialist CF centre with multidisciplinary team support will have overall responsibility for the care of your baby. If you live far away from a specialist CF centre, you may decide to attend a shared care hospital for routine appointments and check-ups. This is referred to as 'shared care'.

Note: Shared care Centres have dedicated and experienced CF staff but may not have a full MDT or may not have access to some specialist investigation procedures/equipment. People with CF will be referred to specialised centres when required.

Paediatric/Adolescent CF Centres

- Children's University Hospital, Temple Street (Dublin)
- Adelaide and Meath Hospital, Dublin, Incorporating The National Children's Hospital (Tallaght Hospital, Dublin)
- Our Lady's Children's Hospital Crumlin (Dublin)

Paediatric, Adolescent and Adult CF Centres

- Galway University Hospital
- Cork University Hospital
- Mid-Western Regional Hospital, Limerick
- Mayo General Hospital, Castlebar
- Our Lady of Lourdes Hospital, Drogheda, Co Louth
- Waterford Regional Hospital

Adult CF Centres

- St Vincent's University Hospital, Dublin (National Referral Centre for Adults with CF)
- Beaumont Hospital, Dublin





Routine Clinic Appointments

Routine Clinic appointments generally take place every 2-3 months though frequency can vary according to your child's individual needs. You should contact the team if you need to see them at any other time.

What happens at Routine Clinic Appointments?

You will meet members of the multidisciplinary team. Medication will be reviewed and any treatment changes will be fully discussed. The visit will also include:

- Routine physical examination
- Measurement of weight, height, and body mass index (over 2 years of age) to assess growth
- Oximetry (measures oxygen saturation of the blood)
- Pulmonary function test (generally over 6 years of age)
- Sputum/cough swab cultures
- Physiotherapy review and/or session reviewing techniques
- Discussion with Dietitian about dietary requirements



Routine Clinic appointments generally take place every 2-3 months.

In some centres the lung function and weight will be monitored and documented in the Pulmonary Function Test laboratory. Any other issue that has arisen with your child's health since the last appointment should also be discussed.

Annual Assessment

Annual Assessment takes place once a year at the Specialist CF centre.

Results from the first annual assessment are a baseline for continuous CF care and the results will serve as a reference for future assessments and measurement of disease progression. The outcomes of the initial assessment will form the basis for your baby's treatment program.

What happens at Annual Assessment?

- A history of all medical and life events since the previous annual review
- A full clinical examination
- Review of physiotherapy techniques and exercise program, adherence to individualised programs and therapies
- Nutritional review by the dietitian including discussion of current diet, enzymes, vitamins and nutritional supplements
- Glucose Tolerance Test (often in alternate years)
- Regular bloods
- Lung function test (over 6 years of age)
- Scans (chest and nasal passages if needed)
- +/- Chest X-ray and +/- CT scan
- +/- Shuttle test (exercise/fitness test)
- DEXA scan (measures bone density test; this scan is usually taken every 2-3 years)
- Sputum sample or cough/throat swab sample is taken. It may be advised that you send these samples in prior to assessment so results are available for discussion

At the end of the annual assessment, the consultant will write a report and discuss the results and treatment plan outlined with you. A written copy of this report may be made available to you, and may also be sent to your GP for reference.

Should you have any concerns or questions about the CF care your child is receiving, then please contact your MDT directly or make an appointment with the CF consultant to discuss your child's care and treatment pathway. CF Ireland are also available to offer general practical advice and support where appropriate.



Cystic Fibrosis Treatment Centres in Ireland

County	Hospital	Consultant	Paediatric / Adult
Cavan	Cavan General Hospital Tel: 049 437 6000	Dr Anne Leahy	Paediatric
Cork	Cork University Hospital Tel: 01 2694533	Dr Barry Plant Dr Michael Henry Dr Muireann ní Chroínín Dr David Mullane	Adult Paediatric
Dublin	Beaumont Hospital Tel: 01 8377755	Prof NG McElvaney Dr Cedric Gunaratnam	Adult
	St Vincent's University Hospital Tel: 01 209 4684	Prof Charles Gallagher Dr Ed McKone	Adult
	Temple Street Children's University Hospital Tel: 01 8748763	Dr Dubhfeasa Slattery Dr Fiona Healy	Paediatric
	The Adelaide and Meath Hospital Dublin, Incorporating the National Children's Hospital Tel: 01 4142000	Dr Peter Greally Dr Basil Elnazir	Paediatric
	Our Lady's Children's Hospital Crumlin Tel: 01 4096100	Dr Paul McNally Dr Des Cox	Paediatric
	Mater Misericordiae University Hospital Tel: 01 8034296	Prof Jim Egan	Lung Transplant Physician
Galway	University College Hospital Galway 091 524222	Dr Mary Herzig Dr Michael O'Mahony	Paediatric Adult
Kerry	Kerry General Hospital Tel: 066 7126222	Dr Fergus Leahy	Paediatric
Limerick	Midwestern Regional Hospital Tel: 061 301111	Dr Barry Linnane Dr Brian Casserly	Paediatric Adult
Louth	Our Lady of Lourdes Hospital Tel: 041 9837601	Dr Amjad Alta	Paediatric
Mayo	Mayo General Hospital Tel: 094 9021733	Dr Michael O'Neill	Paediatric
Sligo	Sligo General Hospital Tel: 071 9171111	Dr Rohininath Tummaluru	Paediatric
Waterford	Waterford Regional Hospital Tel: 051 848000	Dr Animitra Das Dr Mark Rogan	Paediatric Adult

This information sheet was reviewed by CF Clinical Nurse Specialists in June 2012 and May 2013.