

Cystic Fibrosis Service Review



The Cystic Fibrosis
Association of Ireland

– DANGEROUSLY INADEQUATE STAFFING – FACILITIES SERIOUSLY UNSATISFACTORY

Too few staff and a shortage of adequate facilities and services are among the key findings of a major independent review of cystic fibrosis in Ireland.

Completed in 2004 by Dr R.M. Pollock, MPA Health Strategy and Planning, the review concludes that staffing levels are dangerously inadequate and cystic fibrosis services are too thinly distributed over many different locations.

In his report, Dr Pollock also describes the lack of segregation and isolation facilities in some locations as 'dangerous' and says they create significant risks of cross infection.

To address these widespread problems, Dr Pollock makes a series of recommendations. His two key recommendations are:

1. Urgent action to correct the dangerously inadequate staffing position; and
2. The establishment of a small number of adequately staffed and fully supported cystic fibrosis centres.

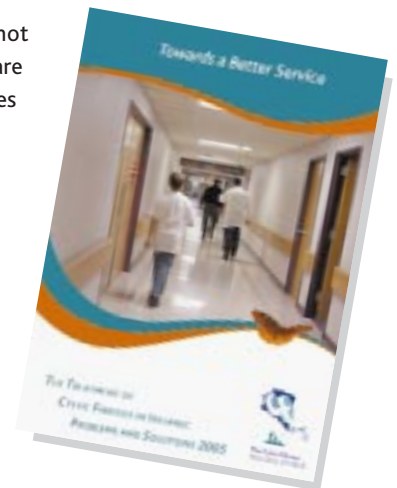
Commenting on the findings, Carl Rainey, Chairman of the Cystic Fibrosis Association of Ireland, said that Dr Pollock's report represented a blueprint for the way services must be urgently developed.

"While it will be no surprise to people with cystic fibrosis and their relatives that words such as 'inadequate' and 'dangerous' appear frequently in the report, it is deeply disappointing that overall services have remained so poor for so long," he said.

"The Association, along with the Minister for Health and Children, Department officials and the new Health Service Executive (HSE), now have a road map that must be rigorously followed as quickly as possible.

"Patients are entitled to services that minimise the potential for cross infection and offer access to appropriate professional multi-disciplinary teams.

"These are not luxuries. They are basic necessities and rights," he said.



COMMENT

News from the Medical and Scientific Council Dr Charles Gallagher, Chairman

The Medical and Scientific Council of CFAI has reviewed and strongly supports the report by Dr Pollock. A major strength of this report is that it is an external, independent review and it compares cystic fibrosis services in Ireland to clearly defined international guidelines. Dr Pollock discusses in detail the major deficiencies in cystic fibrosis care in Ireland. He specifically highlights the totally inadequate staffing position in all CF centres throughout Ireland. He clearly shows that the number of consultants, junior medical staff, dieticians, nurses, pharmacists, physiotherapists, psychologists, secretaries and administrative staff, and social workers is totally inadequate.

The Medical and Scientific Council also strongly supports the development of properly resourced cystic fibrosis centres throughout Ireland so that people with cystic fibrosis can be treated nearer home. The report also clearly confirms the international requirements that all hospital beds for cystic fibrosis patients must be in single rooms. (Continued on Page 7)

T O W A R D S A B E T T E R S E R V I C E

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Ireland has the highest incidence of cystic fibrosis in the world and should have facilities and services that reflect this unenviable position.

Sadly, the review of cystic fibrosis services, carried out by Dr Pollock in 2004, confirms that the opposite is the case.

This newsletter illustrates some of the deficiencies and unnecessary hardships experienced in Ireland by people with cystic fibrosis and their families.

It also highlights what needs to be done to address these deficiencies.

The Cystic Fibrosis Association of Ireland is seeking immediate action in two areas:

1. Delivery of a National Cystic Fibrosis Service

The Government's current commitment to cystic fibrosis is "seriously inadequate".

It must immediately implement a national cystic fibrosis service.

This can be achieved by establishing nine Specialist Cystic Fibrosis Centres that are properly staffed, funded and accredited as recommended by Dr Pollock. This approach is consistent with the recommendations of The Hanly Report.

An estimate of the capital cost to upgrade existing services to Specialist Cystic Fibrosis Centres (excluding St Vincent's) will be in the region of €13.5 million.

To deliver adequate services through these centres, the number of cystic fibrosis staff must increase from the current 40 to 175 – a 438% increase. It is estimated that this will cost an extra €9 million annually.

2. St Vincent's Hospital – the National Adult Cystic Fibrosis Referral Centre

The facilities at St Vincent's Hospital, Dublin are appalling.

Dr Pollock describes them as "seriously unsatisfactory" and "dangerous".

An immediate capital investment of at least €8 million is needed.



Carl Rainey, Chairman
The Cystic Fibrosis Association of Ireland

These investments will improve the quality of care for people with cystic fibrosis and improve their life expectancy. They will ensure they have access to services equal to those available in neighbouring countries.

They will reduce the pressure on A&E from patients who require urgent interventions and they will reduce the threat of cross infection from antibiotic-resistant strains of bacteria.

We cannot underestimate the urgency of the situation.

For example the conditions at St Vincent's Hospital in Dublin are so acute, Dr Pollock warns, that there are serious risks of cross infection from virulent organisms. In his report he says that if an outbreak were to arise it could lead to litigation similar to that which surrounded the Hepatitis C infection scandal.

During the coming months, the Association's primary objective is to highlight to An Tánaiste and Minister for Health and Children, Mary Harney TD, officials at the Department and the HSE, the difficulties and solutions, and consequence of inaction.

You can support us in this campaign by contacting your local TD.

Use this newsletter to make sure they understand the current shortfalls in services and our two priorities, outlined above. Ask for their support and encourage them to do what they can to help.

Details of all TDs and their contact details are available at www.politics.ie.

Additional copies of this document are freely available from the Association: Tel: (01) 496 2433.

RECOMMENDATIONS

Following his review of cystic fibrosis services, Dr Pollock made 11 recommendations:

- 1 Urgent action should be initiated to correct the dangerously inadequate staffing position.
- 2 A small number of adequately staffed, fully supported cystic fibrosis centres should be designated.
- 3 The existing Dublin Centres should remain but the links between the adult and children's units should be strengthened and developed along geographical lines (Temple St*/Beaumont and Crumlin**/Tallaght+/St Vincent's).
- 4 Tertiary paediatric services should be designated.
- 5 Adult provision outside Dublin should be developed urgently to create a balanced service with broad geographical coverage. This would reduce the excessive burden on St Vincent's Hospital. St Vincent's should retain its designation as the Adult Tertiary Centre.
- 6 All beds for patients with cystic fibrosis should be in single rooms with en-suite toilet facilities to prevent the transmission of infection.
- 7 A Microbiology Reference Laboratory should be established in Dublin to support and inform centres and to champion advances in knowledge and treatment. There should be a consultant microbiology service in each centre.
- 8 A Neonatal Screening Programme should be established following the establishment of a logical pattern of joint child/adult CF centres (so as to maximise the potential benefits of screening).
- 9 A structured, regular Accreditation Process should be developed, and form part of the funding methodology.
- 10 A new funding methodology (possibly based on banded 'packages of care') should be developed to create the stability required in the system.
- 11 The CF Registry of Ireland should be maintained and developed.

* The Children's University Hospital

** Our Lady's Hospital for Sick Children

+ The National Children's Hospital

National Referral Centre is "Seriously Unsatisfactory"

In his review of facilities around the country for people with cystic fibrosis, Dr Pollock states that there are huge deficiencies in the provision of adult services and reserves his strongest criticism for those at St Vincent's Hospital in Dublin.

Ironically, St Vincent's is the country's largest centre (currently 304 patients – 60% of the adult cystic fibrosis population) for treating adults with cystic fibrosis yet is in need of the greatest and most urgent attention.



The new development at St Vincent's University Hospital will do nothing to alleviate the problems with current cystic fibrosis services.

Dr Pollock describes the situation at St Vincent's Hospital, which is the National Adult Referral Centre, as "bleak".

"The in-patient provision is seriously unsatisfactory, with CF patients and elderly respiratory patients, cheek by jowl in tightly constrained space; segregation from an infection control point of view is difficult, and the social mix of young CF patients and elderly – some incontinent – patients, is very unsatisfactory. At times CF patients have to be admitted to other, general wards where nursing staff do not have specific CF expertise.

"The CF team members are dedicated and hard working, but their number and conditions are unsatisfactory."

While services for children attending Our Lady's Hospital for Sick Children, Crumlin, on an out-patient basis, will experience significant improvement following the recent opening of a new CF Resources Centre, conditions for in-patients are very poor with segregation and privacy very difficult to achieve.

On Dublin's Northside Dr Pollock describes the facilities at The Children's University Hospital, Temple Street, as very poor. He points out that the hospital will be replaced by a purpose built paediatric hospital which will include multiple isolation rooms, a new respiratory department and will provide a walk-in cystic fibrosis clinic service.

However, this is a long term project and it is unlikely that these much needed services will be available until after 2009.

Outside Dublin, Dr Pollock says that the facilities, with the exception of Drogheda, while unbalanced in favour of services for children, are generally much better.

Shortfall in specialist staff almost 450%

In his report Dr Pollock describes the current staffing for cystic fibrosis as dangerously inadequate.

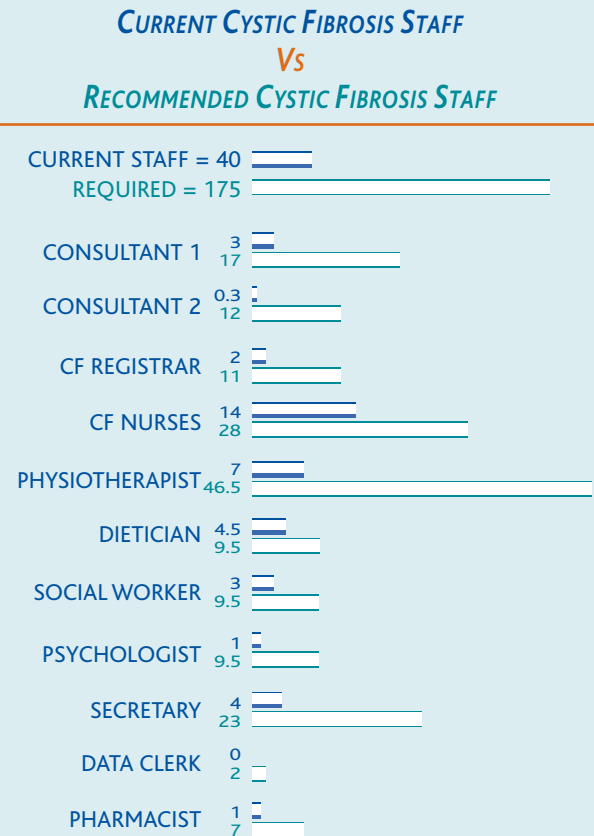
He warns that there is a striking absence of Specialist Registrars, raising concerns about how the future demand for Consultants will be met, and points out that the availability of consultants is further diminished by their heavy general medical on-call responsibilities.

In addition he says that while the lynch pins of the cystic fibrosis services are the Cystic Fibrosis Nurses, Physiotherapists, Dieticians, and Psychologists, their numbers are also totally inadequate.

His detailed analysis reveals that there are in the region of 40 staff serving the total cystic fibrosis population of 1,143. However, based on recognised standards of care, this figure should be 175; there is currently a staff shortfall of 438%. To provide the required staff will cost an extra €9 million annually.

By 2010, factoring in the expected growth in the cystic fibrosis population, the number of specialist staff needed to provide an adequate national cystic fibrosis service will be more than 200.

TABLE 1



Fear of Infection Presents a Real Threat

People with cystic fibrosis are very susceptible to serious infection and, as a result, the cleanliness of their environment is a major concern.

When they do contract an infection, their symptoms can be very severe and can cause permanent lung damage. Treatments are usually aggressive and often require hospitalisation. Some infections can be life threatening.

The danger of cross infection is particularly acute in hospitals where there are inadequate facilities; for example where patients must share rooms and facilities.

John Dolan's daughter has cystic fibrosis and he is worried that she could pick up an antibiotic-resistant infection when she is in St Vincent's Hospital that might disqualify her from a lung transplant, if and when she requires it.

He recently wrote to the Minister for Health and Children strongly expressing his concerns about hygiene practices at the hospital.

According to John, the wards are simply not cleaned properly. "There is dust and fluff in corners, behind doors and around beds. Floors and hard surfaces are not washed frequently enough. Ward toilets and showers are not properly maintained. On many occasions toilet bowls are unclean and stained with faeces. There are often pools of urine on the floor for significant periods," he said.

In his letter he suggested that overcrowded wards, with beds very close to each other, presented an unacceptable risk of cross infection. He also pointed out that the international practice was to keep cystic fibrosis patients with particular strains of bacteria apart from each other and from the general patient population.

While it was not his intention to criticise the staff, he said that many inappropriate practices, such as poor infection control, were being followed because of system management problems and insufficient staff. In his letter he cited two examples:

- His daughter, like all cystic fibrosis patients, is likely to have suspicious bacteria in her sputum at any time. Recently, while an in-patient, a carton containing her sputum was spilled on the floor. A nurse accidentally walked on it and wiped it off her shoe with a tissue. Then without further cleaning she walked around the ward with no apparent regard for the danger of cross infection to other patients.
- In 2002 his daughter was in the A&E for more than 24 hours. During that time she was approached by a doctor with an I/V tray, which was contaminated with someone else's blood. The doctor was about to proceed with an I/V procedure until John protested. The registrar assured him that the incident would be investigated. He has never had a satisfactory explanation.

Overall, he said, infection control practices are not good enough; doctors and nurses do not always wear gloves or wash and sterilise their hands between patients. "For example," he said "sterilising gel containers should be located at the end of each bed."

John said he was glad to see the progress in building a new hospital on the campus at St Vincent's Hospital. However he said the risks to patient care that he outlined were not going to be fully addressed by

the new building. "They are caused by a lack of operating finance, staffing and management issues," he said.

He asked the Minister for assurances that these issues will be effectively addressed.



John Dolan with his daughter Heather

A person with cystic fibrosis describes some of his experiences at St Vincent's Hospital

St Vincent's Hospital is over crowded. It is very difficult to get a bed in the respiratory ward, St Paul's, which has dedicated CF staff and specialist nurses.

Once when I was admitted to the hospital, there was no room in St Paul's, so I was accommodated in another 3-bed ward. It later transpired that one of the patients on this ward had MRSA – the hospital superbug. I only found out about this by chance after overhearing a conversation with the patient telling him he had the bug.

The ward nurses did not know the impact MRSA would have on somebody with cystic fibrosis so I had to request to be immediately transferred. If I had been on St Paul's Ward in the first place the qualified staff would have understood the threat of MRSA and I would not have had to rely on overhearing the private conversations of others for my safety.

On another occasion I was released from hospital on a Thursday to finish out a course of IV antibiotics at home. I was being treated for pneumonia and had been an in-patient for the previous two weeks.

On the Friday evening I got a relapse. Not wanting to add to the Friday evening chaos at A&E, I waited until 10am on Saturday to attend. Despite being on IV antibiotics and being an in-patient for the previous two weeks. I had to wait for 12 hours to be seen. The triage nurse even told me that I should not have 'clogged up' A&E. I complained about this to the specialist CF staff when I eventually was re-admitted. They told me the conditions in A&E were out of their control – I hate to think how long I would have been waiting if I had gone to A&E on Friday night!

Existing Cystic Fibrosis Services Are in Crisis

As people with cystic fibrosis get older, their symptoms generally become more acute and complex.

The cost to meet their needs increases significantly as they become more dependent on medication, in-patient and out-patient services.

A banding evaluation method used in the UK (Table 2) illustrates clearly the relationship between the cost of care and the health of patients.

For example, it shows that it costs ten times less to provide care for people with mild symptoms (€5,500) than it does for people with moderate symptoms (€59,000).

In Ireland the death rate is very much higher than in England, Wales or Northern Ireland, and therefore a greater percentage of Irish patients occupy these higher, more costly, bands.

In the absence of appropriate staff and services, patients will continue to progress to the higher bands more quickly than they should, placing an undue burden on patients and the wider health service.

As the adult cystic fibrosis population increases by 168 during the next five years (2005-2010), the current limited services will face a worsening crisis and be unable to cope.

Properly staffed specialist cystic fibrosis centres will keep patients in the lower, less costly bands for longer and free up the health service to meet other pressing needs.

"...as a result of improving care, child patients will comprise a predominantly 'well' population, whereas, with the greater extension of life into adulthood, an increasing population of adult patients, with more complex manifestations and making greater demands on CF services, will come to exist." Dr Pollock.

TABLE 2

Estimate of the annual cost to care (medication, in-patient and out-patient services) for people with cystic fibrosis in Ireland using the UK model, where patients are banded according to the severity of their disease.

(Source: Cystic Fibrosis Trust (UK) *The Clinical Care of Children and Adults with Cystic Fibrosis Bandings and Associated Costings*, 2004.)

	%	No of Patients***	Total annual cost per patient*
Year of Diagnosis	3	34	€ 14,000
Band 1 – Mild	37	423	€ 5,500
Band 2 – Moderate	17	194	€ 59,000
Band 3 – Severe	24	274	€ 89,000
Band 4 – Extra Severe	16	183	€ 136,000
Band 5 – Awaiting Transplant**	3	34	€ 225,000

* 1 Euro = .70p

**Average figure used.

*** While the Irish patient population has been segmented using the UK percentages, it is likely that a more detailed analysis would show a greater number of Irish patients in the higher bands.

Year of Diagnosis

Some patients may be admitted after they are diagnosed while most will be cared for as out-patients. The out-patient input will be intense and they will spend a lot of time with doctors, CF nurses, physiotherapists and dieticians learning how to manage their CF.

Band 1 – Mild

Patients who only need out-patient care in terms of inputs from physiotherapists, doctors, social workers, dieticians etc.

Band 2 – Moderate

Patients who receive the above and in addition require out-patient intravenous antibiotics 3-4 times a year at home. They may occasionally be admitted to hospital. The input as an out-patient is greater than in Band 1.

Band 3 – Severe

Similar to patients in Band 1 and 2 but essential intravenous antibiotics are received as an in-patient three to four times a year. They may also have diabetes, require feeding gastrostomies and require a higher input overall.

Band 4 – Extra Severe

Patients with severe disease, who attend hospital three to four times a year for intravenous antibiotics and have increasing disease severity. They may have diabetes and more resistant organisms. They may be under consideration for transplantation.

Band 5 – Awaiting Transplant

These patients have usually been in Band 4 for at least a year and need to stay in hospital for four to six months awaiting transplantation or palliative care. They are unable to go home because of oxygen dependence, nocturnal ventilation, and feeding gastrostomies and need intravenous antibiotics every day, sometimes for 2-3 years.

All Patients Must Have Equal Access to Services

In his report, Dr Pollock identifies that the level of care available to people with cystic fibrosis can vary greatly from one location to the next.

He also points out that existing services are in fact too thinly distributed over many small units.

For example, he suggests that the centres in Tralee, Mayo, Sligo and Drogheda do not see enough patients to enable them to maintain an adequate service.

He also points out that nationally, services for adults are available in just four of the 13 centres. While Galway, Mayo, Sligo and Drogheda have some adult services he says that they are mainly paediatric services. The remaining five centres provide services for children only.

The irony of this imbalance is that, because of the progressive nature of the disease, adults usually need more intense levels of care than children.

The shortfall in adult services is a significant long term problem as the number of adults with cystic fibrosis is expected to increase by 168 during the next five years (2005-2010), due to increasing survival rates among child patients (See Table 3).

To address these issues, Dr Pollock recommends the designation of a smaller number of specialist cystic fibrosis centres, each capable of providing the full range of specialist services and personnel for out-patient and in-patient care for children and adults.

This approach will provide a more balanced geographical spread of appropriate services and reduce the excessive burden on the National Adult Referral Centre at St Vincent's Hospital.

It will also ensure that each centre will have the optimum number of patients (children and adults) needed to justify a full team of professional and skilled staff.

"It is not a service to patients and families to provide ease of access at the cost of less than

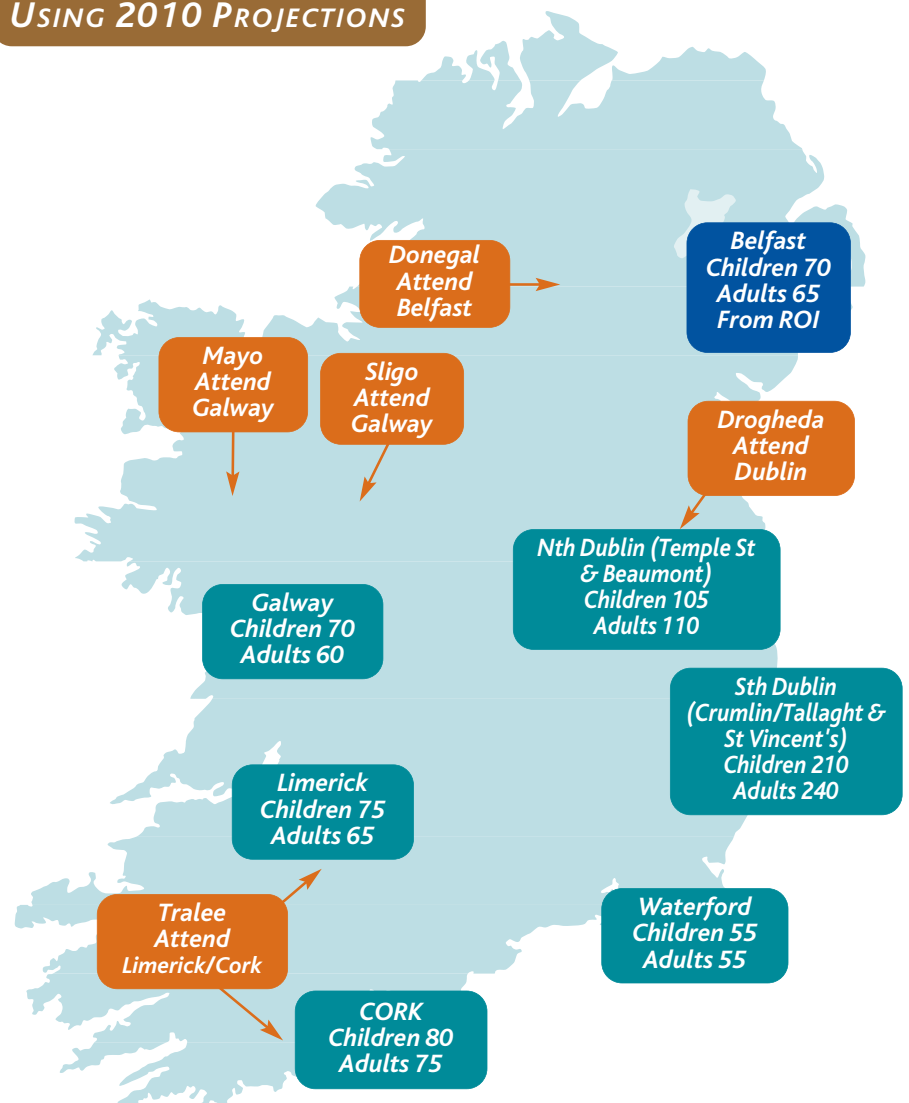
CURRENT CYSTIC FIBROSIS CENTRES

Nth Dublin	Waterford Regional Hospital (C)
Beaumont Hospital (A)	Cork University Hospital (A&C)
The Children's University Hospital, Temple St (C)	Tralee General Hospital (C)
Sth Dublin	Limerick Mid Western Regional Hospital (A&C)
St Vincent's University Hospital (A)	Galway University Hospital (C*)
The National Children's Hospital, Tallaght (C)	Mayo General Hospital (C*)
Our Lady's Hospital for Sick Children, Crumlin (C)	Sligo General Hospital (C*)
	Our Lady of Lourdes Hospital, Drogheda (C*)

A = Adult Only, A&C = Adult & Children, C = Children Only

* Galway, Mayo, Sligo and Drogheda hospitals have some adult services but are mainly paediatric.

PROPOSED LOCATION OF CYSTIC FIBROSIS CENTRES USING 2010 PROJECTIONS



Essential Features of Specialist Cystic Fibrosis Centres

The essential components of Specialist Cystic Fibrosis Centres are specialist staff, appropriate facilities and an adequate number of patients.

The minimum number of patients needed to sustain an adult centre is between 50 and 100. The figure is the same for paediatric centres.

A centre with less patients would find it difficult to provide an adequate service to patients and their families.

In addition to the experienced staff who deal directly with patients, each centre must have access to a range of specialist staff, such as microbiologists, who may never come into direct contact with patients but who provide timely expertise.

Specialist CF Centres should offer patients access to a comprehensive range of essential services and expertise including:

- Care and annual review of patients including early assessment.
- Access to a wide range of treatments and services which require special expertise and specialised procedures.

- Diagnostic and specialised laboratory facilities.
- Psychosocial support.
- Support for the transition from paediatric to adult care.
- Liaison with transplant centres.
- Current research.
- Support for patient involvement in monitoring and development of services including support for patient advocacy.

Out-patient facilities at the Specialists centres should include:

- Sufficient clinic sessions which will avoid overcrowding in waiting rooms.
- Designated areas for day cases.
- Appropriate accommodation for patients and relatives.
- Separate rooms for medical staff, physiotherapists, dieticians, psychologists/social workers and nurse specialists.
- A high standard of hygiene.

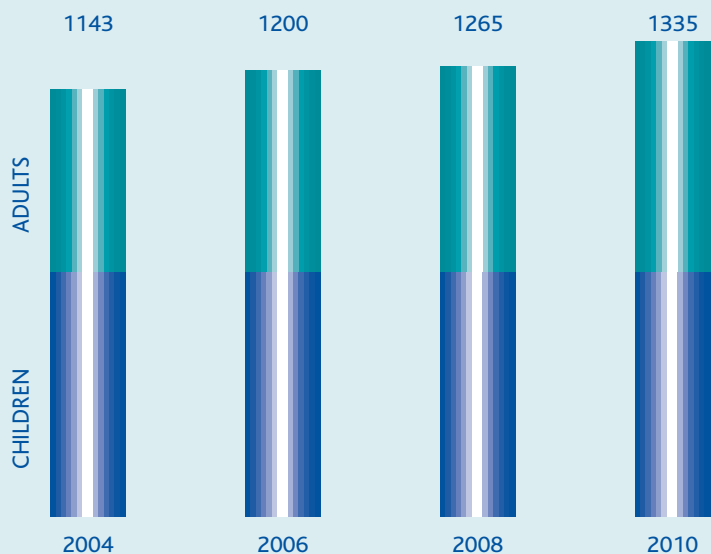
- On site Consultant Microbiology Services.
- Respiratory function equipment.

In-patient facilities at the Specialists Centres should include:

- A clear infection control policy.
- The equivalent of three to five beds for every 50 patients.
- Single bedrooms with en-suite bathrooms.
- Adequate observation and appropriate facilities for parents sleeping in children's rooms.
- Facilities for education and recreation taking into account potential risks of cross-infection.
- Appropriate equipment.
- Arrangements for direct admission to specialist wards when necessary without long delays in A&E, where there are risks of cross infection.

TABLE 3

CURRENT AND PROJECTED NUMBER OF PEOPLE WITH CYSTIC FIBROSIS: 2004-2010



News from the Medical and Scientific Council

Dr Charles Gallagher, Chairman

(Continued from Page 1)

The Cystic Fibrosis Registry of Ireland, which has been set up by Ms Linda Foley, has been one of the "good news" stories in recent years. Dr Pollock highlights the importance of the Registry and the need for further development and expansion of it. We also support Dr Pollock's recommendations about setting up a Microbiology Reference Laboratory and a Newborn Screening Programme for Cystic Fibrosis. Very importantly, Dr Pollock highlights the need for guaranteed and dedicated ongoing funding for cystic fibrosis care.

The Medical and Scientific Council feels strongly that, unless Dr Pollock's recommendations are implemented, the care and outlook for people with cystic fibrosis in Ireland will continue to fall below international standards.

Facts About Cystic Fibrosis in Ireland

- Ireland has the highest incidence of cystic fibrosis in the World. There are more than 1,100 cystic fibrosis patients (45% adults & 55% children) in the Republic of Ireland.
- Cystic fibrosis is also Ireland's most common life-threatening genetically inherited disease affecting one in every 1,600 births.
- Ireland displays a very much higher death rate than does England, Wales and Northern Ireland.
- There is no cure for cystic fibrosis so patients rely heavily on the health system to manage their often severely debilitating symptoms.
- Cystic fibrosis primarily affects the lungs and digestive system but can also damage other organs including the pancreas, liver and reproductive system.
- It causes a build up of mucus in the lungs which leads to a cycle of lung infections and inflammation. The build up of mucus in the pancreas can also make it difficult to digest and absorb food.
- Respiratory infections are the main clinical problems and leading cause of death.
- Because patients are prone to chest infections and malnutrition, the absence of access to qualified staff and appropriate facilities leads to unnecessary visits to A&E units, for emergency relief, rather than Specialist Cystic Fibrosis Centres.
- Cystic fibrosis services are provided in 13 locations around the country.
- The severity of the illness can vary. It generally gets progressively worse with age and becomes increasingly more expensive to manage as symptoms become more acute.
- At one end of the scale patients can be treated as out-patients with input from physiotherapists, doctors, dieticians etc. while others, with more severe symptoms, must remain in hospital and require organ transplantation or palliative care.
- Treatment includes consumption of pancreatic enzymes with food, daily chest physiotherapy, nutritional supplements and tube feeding, antibiotic treatment (including intravenous) and organ transplant.
- The Cystic Fibrosis Association of Ireland was founded in 1963, has 22 branches and 1,500 members. It provides assistance and support for people with cystic fibrosis and their families.

No beds for patients with cystic fibrosis

During the past four years Denise (22) has been regularly admitted to St Vincent's Hospital. In general she stays for three to four weeks at a time.

What worries Denise and her family most are the ever increasing hurdles she must overcome to secure a bed and urgent specialist care when she becomes unwell.

Here's what she had to go through to get a bed the last time she was admitted to St Vincent's Hospital:

MONDAY:

12.30pm After contracting another infection, Denise decides that she needs hospital care and presents herself at the A&E at St Vincent's Hospital. There is nowhere else she can go.

11.00pm After ten and a half hours, Denise decides that the waiting is making her worse so she returns home for some rest and plans to return the next day.

TUESDAY:

1.00pm Denise presented herself again at A&E at St Vincent's.

WEDNESDAY:

7.00pm Denise gets a bed in St Paul's Ward. Between Mon and Wednesday Denise had been waiting in A&E for 40 hours.

There is no dedicated cystic fibrosis ward in St Vincent's Hospital (which is the country's National Adult Referral Centre) so Denise considered herself lucky to get a bed in St Paul's, the respiratory ward. The alternative would have been a bed in a general ward where staff do not have the essential specialists knowledge of cystic fibrosis.

While Denise's mother Marie accepts that there are a limited number of beds available, she believes it is unfair and wrong for Denise to have to wait in A&E for so long for a bed.

"Denise has lived with this disease all her life. She knows when she needs help. Why could she not have been assessed, sent home and phoned as soon as a bed became available," she said.

"If this situation continues patients who need help may not seek it. What will happen then?"

The other aspect of St Vincent's that Denise finds difficult to accept is the lack of facilities specifically for cystic fibrosis patients.

"For example the nebulisers can be noisy and when you are sharing a ward with five other patients, who are often elderly, it can be very disturbing for the others and make things unnecessarily difficult for everyone.

"And of course, being so close to other patients with severe respiratory problems, there is the constant fear of catching another infection," said Denise.

"It is difficult enough to cope with cystic fibrosis without having to put up with this. We need a ward to ourselves and we can't wait forever," she said.