



Submission from Cystic Fibrosis Ireland to the Commission on Energy Regulation on the Economic Regulation of the Public Water Service Sector

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Contents

Introduction and Summary	3
Summary of key points	3
What is Cystic Fibrosis?	4
What causes CF?	4
Discussion of Key Points.....	5
• General Affordability Issues:	5
• Hygiene & infection control in the home	5
• Dehydration in people with CF	5
• Pancreatic Complication in CF	5

This position paper was drafted by Katie Murphy, Research & Development Officer at Cystic Fibrosis Ireland with the support of colleague Alica May, Services and Information Officer

Introduction and Summary

The rationale for this submission is to highlight the additional strain which will be placed on people with Cystic Fibrosis (PWCF) and the households in which they reside when the impending water charges are introduced next year.

This submission is based on the concerns of our members, highlighting the additional water needs of this patient population and also the need to ensure the provision and affordability of basic services to the most vulnerable populations in society.

Summary of key points

- Water is a basic human right and therefore mechanisms ensuring affordability and access for Ireland's vulnerable households, including those with a medical condition, must be established and implemented before charges are introduced. This can be achieved through the allocation of free water allowances and medical allowances.
- A large proportion of People with CF (PWCF) are now managing their illness in their home. This requires a rigorous daily routine of treatments, such as taking numerous nebulisers, airway clearance (including exercise) and often over 30 tablets per day. The need for water for **equipment cleaning**, adopting correct **hygiene procedures**, personal hygiene after **exercise** and large volumes of **drinking water** are essential to the management of this illness.
- The majority of PWCF are pancreatic insufficient, which is generally managed through pancreatic enzyme replacement therapy. However, this complication often causes an increased volume of protein and fat in the bowls, resulting in diarrheal symptoms and increased use of the toilet.
- Cystic fibrosis can cause a person to become easily dehydrated or to have very low salt levels. This makes it very important for people with cystic fibrosis to drink high volumes of water on a daily basis.
- Households with a medical condition, such as Cystic Fibrosis, are identifiable through medically assessed payments, such as the Long-Term Illness scheme & the medical card scheme or through social supports, such as domiciliary care allowance, carers allowance, disability allowances, etc.

What is Cystic Fibrosis?

CF is Ireland's most common life threatening inherited disease for which there is no cure. Ireland has the highest incidence of Cystic Fibrosis in the world with almost 7 in every 10,000 people with the disease. The incidence of Cystic Fibrosis in Ireland is almost three times the average rate in other EU countries and the United States¹. According to the latest annual report from the Cystic Fibrosis Registry of Ireland (CFRI) in 2012, there are 1,140 individuals with CF living in Ireland – over half of CFRI-registered PWCF were aged 18 years or older (52.2%), and the adult population continues to increase on an annual basis². The median age of death in Ireland is 25 years of age, though those born in later years can expect to live into their 30's and beyond.

What causes CF?

CF is caused by mutations in the cystic fibrosis transmembrane conductance regulator (CFTR) protein, which affects the regulation of absorption and secretion of salt and water in various parts of the body, including the lungs, sweat glands, pancreas, and gastrointestinal tracts. This results in a sticky build-up of mucus in the lungs and digestive tract making it difficult to clear bacteria and leads to repeated cycles of lung infections and inflammation, which eventually leads to irreversible damage of lung tissue³. Symptoms reported by PWCF vary significantly in severity, from very mild to debilitating. The most common symptom associated with CF is recurrent chest infection, which results in lung damage, with the majority of death's occurring through respiratory failure. Other medical issues associated with CF include; CF-related diabetes, osteoporosis, malnutrition, liver disease and infertility, particularly in males.

People with CF (PWCF) account for some of the heaviest and most consistent users of the health system in Ireland as a result of ongoing routine and annual assessments, and inpatient admissions due to exacerbations.

PWCF must undergo a daily routine of physiotherapy, nebulised medications, airway clearance and enzyme replacement therapy when they are well. During times of ill health, exacerbations and lung 'flare-ups' greater levels of treatment and care are necessary, often requiring hospitalisation or the administration of Intravenous (IV) antibiotics in the home.

¹ Farrell PM. Journal of Cystic Fibrosis 2008 Sep; 7 (5) 450-453 which revealed a mean prevalence of 0.737/10,000 in the 27 EU countries which is similar to the value of 0.797 in the United States and only one outlier, namely the Republic of Ireland at 2.98/10,000 population. Recently revised to three times the average in the US and the EU.

² Cystic Fibrosis Registry of Ireland Annual Report 2012

³ Salvatore, D., R. Buzzetti, et al. (2011). "An overview of international literature from cystic fibrosis registries. Part 3. Disease incidence, genotype/phenotype correlation, microbiology, pregnancy, clinical complications, lung transplantation, and miscellaneous." *Journal of cystic fibrosis: official journal of the European Cystic Fibrosis Society* 10(2): 71-85.

Discussion of Key Points

- **General Affordability Issues:**

With average annual water charges expected to be in the region of €300–€400 per household, water charges will not be affordable for a large number of people, including households with essential water needs to the care provided for a loved one with a medical condition. The cost of disability has been estimated at a third of average weekly income. (Cullinan, J., Gannon, B. and Lyons, S. (2010), 'Estimating the Extra Cost of Living for People with Disabilities', *Health Economics*.) The Commission on Energy Regulation must ensure that water affordability strategies are in place to support these households, for example, through free water allowances, medical allowances or bill capping.

- **Hygiene & infection control in the home**

Historically, a large proportion of time for a person with CF (PWCF) was spent in the hospital; however, advancement in treatments and the development of new therapies has seen the hospital becoming less central to the care of PWCF, with a large proportion of treatments being carried out in the home. This shift to home-based treatment now means that infection control and hygiene is not simply an issue in the hospital, but needs to be considered significantly in the home.

Cleaning and sterilisation of reusable respiratory therapy equipment are essential to prevent infections of patients with CF. Personal hygiene is also very important for PWCF, particularly where there is more than one PWCF in a household. PWCF are susceptible to infection, and also pose a very significant risk to one another. Personal hygiene, such as hand washing, is one of the best ways to prevent the spread of infection.

- **Dehydration in people with CF**

People with CF are more susceptible to dehydration as high levels of sodium are lost through sweat. PWCF must be especially vigilant during times of excessive sweating – such as exercise or exacerbation. It has also been well-established that drinking high levels of water can help to loosen thick, sticky mucus in the lungs of PWCF, aiding airway clearance.

- **Pancreatic Complication in CF**

The majority of PWCF are pancreatic insufficient, which is generally managed through pancreatic enzyme replacement therapy. However, this complication often causes an increased volume of protein and fat in the bowls, resulting in diarrheal symptoms and increased use of the toilet.

