

Specialist Services Committee backs expansive strategy for improving cystic fibrosis patient care

Cystic fibrosis treatment has changed drastically in the last 50 years, and as a result, the median age of survival has risen from 4 years in 1960 to 52 years in 2018. In BC in 2020, 62% of residents with cystic fibrosis (CF) are adults, requiring treatment for issues like metabolic bone disease, diabetes, and depression. An effort by CF Canada to coordinate and streamline patient care has finally borne fruit in three significant projects supported by the Specialist Services Committee (SSC).

The first of these projects began in 2015 when Dr Pearce Wilcox, medical director of the Adult Cystic Fibrosis Program at St. Paul's Hospital, undertook a Specialist Services Committee quality and innovation (Q&I) project called Cystic Fibrosis in BC: Optimizing care across the age continuum. I was part of his team, and for more than 3 years, alongside BC CF representatives, PHSA administrators, specialists, and allied health professionals, we carved out the building blocks of integrated CF care from childhood to adulthood.

As part of this effort, we developed a sustainable planning platform for adults and children, called Tiers of Cystic Fibrosis Service in BC.¹ The framework we wrote features the first made-in-Canada CF Standards of Care² and identifies who is responsible for delivering every kind of health care to those with CF.

Adults with CF, for example, are at increased risk of bowel cancer because of the involvement of the gastrointestinal tract with the disease.

They require screening beginning at 40 years of age, but because of the effects of CF on their bowel tracts, colonoscopies can be especially difficult. In addition, the sedation that might ease a colonoscopy may not be appropriate because of lung issues caused by CF. While CF specialty clinics can't offer colonoscopies themselves, Tiers of Service recommends involving the family physician, who would detail the particular patient's issues in advance to the gastroenterologist conducting the screening for a smoother process.

I was the Q&I physician lead on the second of the projects, created to support the screening and treatment of mental health by BC's CF clinics. This project helped inform the Anxiety and Depression pathway³ of the Tiers of CF Service platform. Already being implemented, it recommends that CF clinics regularly screen patients and their caregivers to identify anxiety and depression needs and risks, recommend support services, and make referrals to psychiatrists or emergency assessors.

In September 2019, Dr Wilcox's team presented the results of the third of these projects, the Cystic Fibrosis Provincial Initiative, to PHSA, which will soon initiate a BC Cystic Fibrosis Health Improvement Network (HIN). The network will facilitate the standards of care we established. Starting this September, it will determine how the best patient care can be achieved by bringing together the specialists, primary physician, and allied health workers each patient needs, whatever their age.

The physicians on the HIN working group, of which I may be a member, will be supported by the Health System Redesign Initiative, which supports time-limited system redesign projects.

This HIN represents at least 10 years of unwavering effort by many, including the CF community, BC's Ministries of Health and Mental Health and Addictions, the PHSA, the Joint Clinical Committees, and allied health providers. Over the course of my 30-year career, I've watched BC residents with CF struggle every day. I'm grateful that we're doing what we can

Sixty-two percent of residents with CF are adults, requiring treatment for issues like metabolic bone disease, diabetes, and depression.

to ensure that individuals with Canada's most common fatal genetic disease, and their caregivers, get the very best quality of care. ■

—Ian Waters, MD (retired)

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