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Select Committee on Cost of Living
PO Box 6100
Parliament House
Canberra ACT 2600
Via email: costofliving.sen@aph.gov.au

Dear Committee,

Cystic Fibrosis Cost of Living Submission

We are writing to you on behalf of individuals living with cystic fibrosis (CF) to provide input for the Select Committee's inquiry into the cost-of-living pressures facing Australians and related matters. As you may be aware, cystic fibrosis is a genetic condition that affects the whole body, including the lungs, sinus, and digestive systems. CF has no cure and requires complex and costly medical treatments, therapies, and medications to manage symptoms to support an improved quality of life. Currently, 3,738 Australians are living with CF, and over half of the CF population are adults. Further, every 4 days someone is diagnosed with cystic fibrosis in Australia.

Living with cystic fibrosis presents unique financial challenges for individuals and families, compounded by the broader economic pressures faced by all Australians. The cost of healthcare, including medications, hospitalisations, and specialised treatments, constitutes a significant portion of expenses. Additionally, the need for specific dietary requirements and medical equipment adds further strain to our financial resources.

The financial burden of living with cystic fibrosis, coupled with the increasing costs of food, fuel, rent, and other household essentials are unaffordable. The necessary pharmaceutical costs are adding significantly to the burden of the disease. This is amplified for people living with cystic fibrosis because there are a multitude of medications required to manage the complexity and comorbidities associated with the disease.

As the national peak body, Cystic Fibrosis Australia, along with our state and territory members, is calling on the Federal Government to urgently review the cost of living for people with rare diseases and chronic conditions.

Considering the Committee's focus on exploring ways to ease the cost-of-living pressures, we urge consideration of the following points:

1. **Access to Affordable Healthcare:** There must be equitable access to essential healthcare services, including access to care under mental health plans, especially as cystic fibrosis is a lifelong condition, and medications for individuals with cystic fibrosis should not be further burdened by this cost-of-living crisis.
2. **Financial Assistance Programs:** Targeted financial assistance programs tailored to individuals with chronic illnesses like cystic fibrosis will help alleviate the financial pressures associated with medical expenses, including out-of-pocket costs for treatments and therapies. Such a program can cater for the dynamic nature of chronic conditions, where unexpected, acute exacerbations (such as organ failure) can trigger a rapid decline in the socioeconomic circumstances of individuals and families. Financial assistance programs would address unexpected and urgent needs for support, as a safety net, until the individual or family are able to access further government support.
3. **Financial Relief Measures:** This crisis presents opportunities for financial relief measures, such as increased deductions/rebates, for expenses related to managing chronic illnesses, including medical appointments, prescription medications, and necessary medical equipment.
4. **Supportive Government Services:** Strengthen and expand government services that provide practical assistance to individuals living with cystic fibrosis, such as disability support services, and home care assistance, and increase access to the National Healthcare Card for people living with cystic fibrosis. This

should also expand to the inclusion of CFRD for automatic eligibility for NDSS registration. The current individualised application process creates a further inequitable healthcare burden, including stress and financial strain, on people with CF. They wait longer for access, often with limited understanding or visibility of their application's progress. Medical professionals must complete detailed, certified paperwork to justify what is considered "special access" rather than equitable access. Automatic inclusion for this small population relative to Type 1 and 2, would also relieve administrative load in the healthcare system.

We believe that addressing these issues will not only alleviate the financial strain experienced by individuals with cystic fibrosis but also contribute to building a more inclusive and supportive society for all Australians facing the challenges of chronic illness.

Thank you for considering our submission. We welcome the opportunity to provide further input and participate in the Committee's inquiry process.

Warm regards,

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