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Patron-in-Chief The Hon. Alex Chernov AO, QC, Governor of Victoria

Cystic Fibrosis Victoria Submission

to the Senate Inquiry into Out-Of-Pocket Costs in Australian Healthcare.

July 2014

Cystic Fibrosis Victoria (CFV) is very concerned by the current trends in increasing out of pocket expenditure by Australian health consumers. These costs particularly impact people with chronic disease, and further disproportionately impact people with life long chronic diseases such as cystic fibrosis (CF).

The financial burden of cystic fibrosis

Cystic fibrosis is a life-long condition with a large management burden which financially impacts both families and individuals affected by CF. It is an extremely complex condition, which affects multiple body systems, and requires frequent contact with both primary and tertiary healthcare. Maintaining health or slowing disease progression requires an intensive daily treatment regime which can include:

- Taking multiple medications and supplements – typically between 10 and 20 different types of medication each day often with different delivery methods (oral, injected, nebulised) which require additional medical equipment;
- Undergoing intensive airway clearance physiotherapy each day which involves specific pieces of equipment;
- Maintaining a high level of exercise and fitness;
- Eating a large amount of food and nutritional supplements to counteract poor absorption and meet the increased energy demands that are a typical feature of CF;
- Having frequent contact with both primary and tertiary healthcare, including frequent and lengthy (10 – 14 day minimum) hospital visits, often multiple times per year.

Each of these demands places its own financial burden on families and individuals impacted by CF. For example, most people with CF will reach Pharmaceutical Benefits Scheme (PBS) safety net each year, and often early in the year. It is not uncommon for an adult with CF who is working and does not have a Health Care Card to spend between $2,000 and $3,000 annually on medication. Additionally, there are many other unsubsidised costs associated with CF. These include:

- Physiotherapy and medical equipment;
- Nutritional supplements;
- Fitness equipment or memberships;
- Expenses associated with attending outpatient appointments at one of only three Victorian hospitals that manage people with CF - such as hospital parking, travel expenses, accommodation expenses (for people outside metropolitan Melbourne); and

- Expenses associated with hospitalisations for families/carers of a person with CF – including travel, accommodation, meals, parking etc.

Case Study 1: Family

The Jones family have five children; two with cystic fibrosis (CF) . They are required to travel up to two hours to Melbourne for their CF care at [redacted]. The family are a sole income family; dad works full time to provide for the family. Their monthly wage is around $5,400. The family have around $400 left a month after all bill and CF related expenses are paid for food and other incidentals.

CF Care expense for each child:

- *Medication and supplement cost approximately $130 per month*
- *Airway clearance equipment :*
  - *Twice a day nebulised medication- cost of equipment $525 (once off), $200 handset replacement annually,*
  - *Flutter $59 (once off)*
- *Specialist appointments every three months*
  - *Parking costs: $25 per appointment*
  - *Petrol cost: $50 per appointment*
- *Hospital admissions (10-14 day minimum)- currently 2-3 times a year (mum stays in hospital with the children)*
  - *Parking: $120 per admission*
  - *Food: $200 per admission*
- *Additional food and supplements: $150 per month*

Though the two children with CF have Health Care Cards through their Disability Support Pension the families is still out if pocket approximately $500-$600 a month for CF related cost. Without the Health Care Card this cost would be approximately $800 a month and would be out of reach for this family and many others in similar situation.

CF can also impact ability to work. This can means that in families where a child or children have CF, one parent may choose not to work, work fewer hours or go back to the workforce later, to accommodate the management of their child's treatment needs. Additionally, parents or carers who do work often have to take extra time off work to care for someone with CF who is unwell, to attend appointments, or to stay in or near the hospital when they are admitted.

Adults with CF may struggle to work due to their health, or may dip into and out of the workforce, and on and off Centrelink benefits (primarily DSP), as their health changes throughout their lifetime. Adults with CF who do work are more likely to work part time than adults in the wider community, and more likely to require additional time off work for hospitalisations. This can mean that adults take annual leave, leave without pay, or participate in purchased leave arrangements to

accommodate time in hospital. Some adults with CF choose to run their own businesses from home to better accommodate their healthcare needs, but this can mean issues with maintaining a steady income and longer term financial planning (eg superannuation).

Both the high out of pocket costs, and the need to adapt employment to the management of CF, can mean that individuals and families impacted by CF have less money available for both essential costs and non-essential spending. Cystic Fibrosis Victoria works hard to provide some additional subsidies to ease some of this financial burden on families and individuals, but can not keep up with the rate of rise in out of pocket costs for our community.

The impact of co-payments

Cystic Fibrosis Victoria is also very concerned about proposals contained in the recently released National Commission of Audit Report to introduce an up-front payment of up to $15 (reduced for people on concession cards) for visits to general practitioners and pathology services. CFV is also concerned about any proposals to increase the co-payment for medication provided on the PBS (beyond existing co-payments).

CFV endorses the research into co-payments by the Consumer Health Forum of Australia in their March 2014 Report “Empty Pockets: Why co-payments are not the solution” (author Jennifer Doggett) which found that:

- The introduction of co-payments results in decreased access to health care (strong evidence);
- This decrease in access is proportional to the size of the co-payment (strong evidence);
- The impact of co-payments differs across different population groups and is greater for the elderly (strong evidence), people on low incomes (strong evidence) and people with chronic illnesses (medium level evidence);
- There is no evidence that the decrease in health service utilisation due to the introduction in co-payments is in unnecessary or low-value services. There is limited evidence that the decrease occurs in both high value and low value services; and
- There is no evidence for overall cost savings as a result of the introduction of co-payments and limited evidence for increased downstream health care costs.

These findings indicate that families and individuals affected by CF, especially those facing financial hardship, will be significantly impacted by any future copayment increases. These financial impacts may directly contribute to people either delaying visits to primary health services and/or placing more demands on health providers in tertiary centres. These proposed changes and potential impacts come at a time when tertiary health providers in the CF sector are looking to more actively engage with primary practitioners, to better coordinate the care of CF patients between community services and hospital outpatient clinics.

The role of private health insurance

Private health insurance has little role in CF care, and does not serve to reduce the significant out-of-pocket costs incurred by people with CF and their families. Due to the high and lifelong costs it is very expensive and difficult for people with CF to find an insurer who will cover their CF care. In addition, CF-specific care is only provided through three public hospitals in Melbourne, with no private provider options. Finally, even if someone has private health insurance to cover non-CF related

hospital care, the complexities of CF means that CF care often needs to be provided alongside non-CF related care or procedures. For these reasons, most people with CF are not covered by private health insurance.

The role of the PBS

Finally, Cystic Fibrosis Victoria and the CF community are concerned about the ongoing delays between medication approval by the Therapeutic Goods Administration (TGA) and medication inclusion on the PBS. While the vital role the PBS, and the PBS safety net, plays in reducing the costs of CF management has already been outlined in this submission, it is very concerning that treatments which have been approved for use by the TGA are not made readily available and affordable through the PBS, and instead go through a lengthy negotiation process in both the Pharmaceutical Benefits Advisory Committee and Cabinet which can delay listing of medications by months or even years. Current genetic therapies for cystic fibrosis which show great outcomes in terms of symptom reduction, improved lung function, improved weight, and improved quality of life are priced at a cost that is nearly universally unaffordable without subsidy, and yet that subsidy is currently being significantly delayed due to lengthy bureaucratic processes. Cystic Fibrosis Victoria feels strongly that the processes for medication approval on to the PBS need to be streamlined and transparent, to both reduce the stress and anxiety on patients and families who could benefit from new treatments, and to reduce costs for families who choose to try and pay for expensive treatments out of their own pockets.

People with cystic fibrosis need affordable access to multidisciplinary care and support in both the primary and tertiary care systems, as well as affordable access to the most effective treatments and technologies to best manage their condition, delay disease progression and remain productive contributors to our society. It is unavoidable that people and families impacted by a complex and demanding condition such as CF will have some higher health related costs than the general public. However, what is avoidable, are unnecessary and burdensome costs such as primary care and pathology copayments and increases in PBS costs which disproportionately shift the burden of paying for our healthcare system onto the individuals and families who can least afford it.

Sincerely,

Felicia Welstead
Acting CEO
Cystic Fibrosis Victoria