15/6/2018

CYSTIC FIBROSIS ACT

ACT Legislative Assembly Estimates Public Hearing 15 June 2018

Cystic Fibrosis Facts

Cystic Fibrosis (CF) is the most common life shortening genetic condition in Australia. The average life expectancy for Australians born today with CF is approximately 38 years. On average, one Australian child is born with CF every four days.

Children with CF tend to have recurrent chest infections and breathing problems and the condition worsens with age. Over time, lungs become permanently damaged. ***The lifelong care of a Specialist Respiratory Physician is essential.***

As the pancreas doesn't produce the usual enzymes for digestion, people with CF can become malnourished. ***A Dietician is an key part of the CF care team.***

Approximately 40% of people with CF will develop diabetes. ***Regular consultations with an Endocrinologist are a necessity.***

And up to 30% will develop liver disease. ***The involvement of a Gastroenterologist ensures liver function is monitored accurately.***

Most people with CF will take 60 or more tablets a day including enzyme replacements, high dose multi-vitamins and salt. ***A specialist CF nurse works closely with a pharmacist and dietician to ensure that medications and supplements are still appropriate and doses are correct.***

Managing CF is lifelong, ongoing and relentless including tough physiotherapy regimes and hospital admissions several times a year. ***Physiotherapy to clear lungs and improve fitness is a crucial aspect of CF care. Expert and up to date advice is needed to maintain the daily regime.***

Adults with CF are increasingly impacted by the costs of maintaining their fitness and medication regimes.

People with CF should not spend time together due to the high risk of cross infection. ***Isolation and the inability to spend time with those who share your experience has a very negative impact on mental health.***

There are significant mental health implications for all involved from the stress of living with a life limiting condition. ***Specific psychological support is needed throughout both an individuals and their families journey with CF.***

There is no cure for cystic fibrosis. However, due to improvements in medications and treatment, people with CF are increasing living longer and healthier into adulthood and contributing to society. ***They rely on the ongoing care and support of their healthcare teams.***

Cystic Fibrosis Care in the ACT

The Canberra Hospital Cystic Fibrosis Clinics currently treat **53 adults** and **40 children** with CF. Some of the children are in a shared care arrangement with interstate hospitals.

The Paediatric Clinic commenced in 2003 and the Adult Clinic commenced in 2014.

Prior to these dates, CF patients in the ACT sought treatment at centres interstate or were cared for through their GP and referral to relevant specialists. Despite CF clinics being available in the ACT, some local people with CF still choose to travel interstate for care. In the case of Paediatric patients, 20 are treated interstate partially due to the lack of capacity in the local clinic.

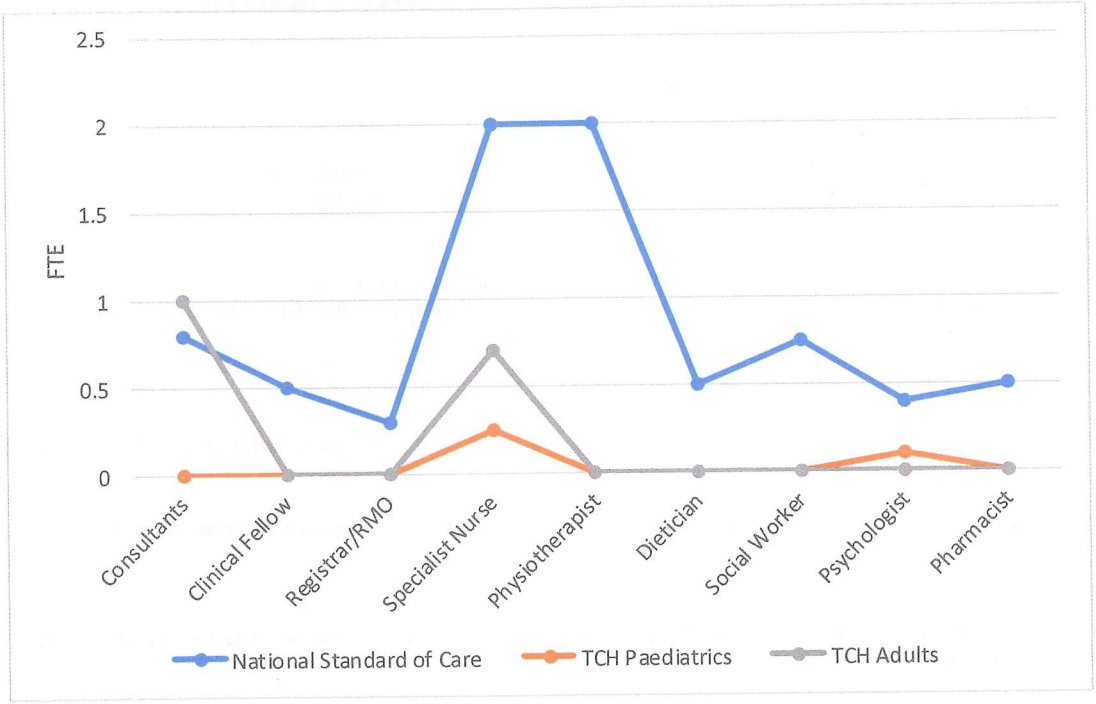
The Canberra Hospital staffing resources in place to manage and treat CF patients are significantly below the Cystic Fibrosis Standards of Care for Australia, as endorsed by the Thoracic Society of Australia and New Zealand and the Royal Australasian College of Physicians. Indeed, despite significant increases in the number of patients over time, the staffing levels at The Canberra Hospital have barely altered.

The staffing problem within the teams is such that if a member of the team goes on leave, clinics can often not run as the position cannot be backfilled from anywhere else within the hospital. A cancelled clinic can seriously impact the health of a person with CF and lead to further complications and hospitalisation.

With increasing populations at both Adult and Paediatric level, failing to meet the standard of care within The Canberra Hospital CF clinic teams will result in reduced care to patients, increased admissions to hospital and poorer health outcomes for ACT people with CF.

A Snapshot of The Canberra Hospital CF Teams

The chart below illustrates the CF dedicated staffing level recommended by the National Standards of Care for an Australian CF Centre treating 50-75 patients versus the current staffing levels at The Canberra Hospital (numbers provided by the relevant clinical staff on 14 June 2018).



NOTE: The line indicating the National Standard of Care is per clinic, not a combined standard covering the adult and paediatric clinics.

At The Canberra Hospital, the only funded positions for CF are the adult consultant, adult nurse (at 0.7FTE) and paediatric psychology services (at 0.02FTE).

All other allied health services, as indicated in the chart above, which are essential to the care of a person with CF, are not dedicated positions. The services are provided by the relevant departments in the Hospital and usually filled by a person with an interest in CF. However, if that person is absent, they are rarely backfilled and care of the patient is impacted. Extra to the standard of care, essential services related to the treatment of CF patients, such as Respiratory Function Testing, have no time allocated to the CF team.

The allied healthcare staff involved fit the care and management of CF patients into their workload because they feel it is important. **These positions are not funded.**

Psychology services play a central role in cystic fibrosis as the condition impacts not only the individual, but also their family members. There is currently no Psychology FTE allocated to the Adult CF care team. Given the high incidence of anxiety and depressive symptoms in this population there is an urgent need for Psychology to be a dedicated part of the team but this cannot be provided without additional funding. Adult patients can only access psychology services while they are an inpatient. Otherwise, they are referred to external services which are often private and incur cost.

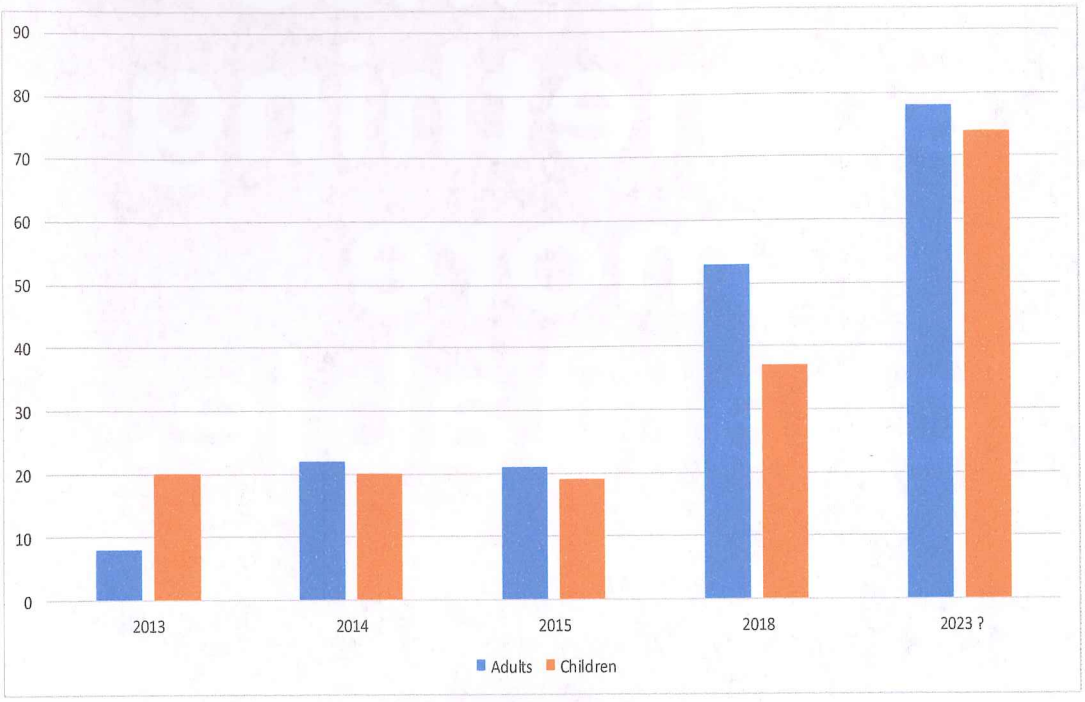
In terms of the Paediatric Care team, a clinical psychologist attends clinics but only sees those patients identified by the team as requiring assistance. Paediatric CF patients are also able to access our outpatient Psychology Chronic Illness clinic as part of the general Psychology services.

A further challenge for adult CF patients is that their clinics are held at the Belconnen Health Centre. This is as a result of previous space limitations at The Canberra Hospital. Having the clinic space away from the hospital means that adult patients must travel from one side of Canberra to the other if they require follow up services. There is a risk that this leads to non-compliance with treatment regimes. We understand that potential clinic space may now be available at The Canberra Hospital for the relocation of the Adult Clinic however no funding has been allocated to make the necessary move.

In terms of other specialist medical care necessary, an Endocrinologist visits the Adult clinics quarterly, when available but is unable to visit the Paediatric clinics. Conversely, a Gastroenterologist travels from Sydney to visit the Paediatric clinic but there is no specific Gastroenterology cover for Adults.

A Glimpse at the Population

The chart below illustrates the growth of the CF population being treated at The Canberra Hospital since 2013. It also shows in the final column the potential size of that population in 5 years. This clearly demonstrates that the population is increasing and will continue to do so. It is therefore essential that the care needs of these people is accounted for in future ACT Health budgets.



2013-2015: This data provided by the Cystic Fibrosis Australia Data Registry for the years 2013-2015

2018: Actual numbers in the Adult and Paediatric clinics on 14 June 2018

2023: Projected numbers based on current growth numbers of the Adult clinic, transition from the Paediatric clinic to the Adult clinic and the transfer of all interstate Paediatric patients back to the ACT (assuming adequate capacity).

Key Issues for Consideration

The Adult and Paediatric Cystic Fibrosis Clinics are significantly under resourced and underfunded. They do not meet the National Standard of Care for Cystic Fibrosis.

Poor and unreliable access to essential care and treatment for their condition puts ACT residents with cystic fibrosis at increased risk of serious declines in health and more regular, prolonged hospital admissions.

Prolonged hospital stays increase the risks of infection for people with CF, further undermining their health.

Mental health issues are significant for people with CF and their families and should be a priority for funding and support.

A well funded and resourced Cystic Fibrosis service in the ACT will have the significant positive results of:

- Improving the overall health and wellbeing of local CF patients, allowing them to contribute socially and economically to the Territory.
- Reducing the number and length of hospital stays for CF patients, freeing up beds.
- Dedicated allocation of the allied health team, reducing workplace stress and risk of errors in treatment and care.

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