



Cystic Fibrosis Queensland Limited
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Title: Assessor training to understand the complexities of cystic fibrosis.

Managing cystic fibrosis is extremely challenging

Cystic fibrosis (CF) is an insidious and invisible condition. It impacts every aspect of a sufferer's life including mental health and creates social isolation. Living with cystic fibrosis is extremely challenging, increasingly so as it progresses.

The severity and symptoms of cystic fibrosis vary greatly between people. Sufferers are impaired in multiple ways, especially from chronic and extreme fatigue as their bodies fight ever present lung infections. They often get insufficient sleep due to breathing difficulties/coughing at night. Those who have mild or moderate lung disease appear healthy, but this appearance can be misleading as they frequently battle brutal fatigue that greatly interferes with daily life. For those living with severe lung disease, cystic fibrosis often prevents them reaching their goals and live a full and complete life.

Managing cystic fibrosis is time consuming

Every day of the year sufferers need to spend hours on time-consuming but essential treatments multiple times per day (e.g. airway clearance, inhaling medications via nebulisers, taking numerous medications, exercise therapy, consuming large meals and additional snacks throughout the day to maintain proper nutrition, taking essential nutritional supplements etc). Failure to adhere to their medically prescribed treatment plans inevitably leads to 1) continually diminished functional capacity and greater treatment burden in the short term often with associated hospitalisations and greater irreversible impairment in the longer term.

The health system provides sufferers with insufficient support to manage their disability in the community. What it does well is 1) prescribing medications and 2) providing reactive care when sufferers experience episodic 'exacerbations'. For example, people with cystic fibrosis receive

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intravenous antibiotics during hospitalisations of 2-4 week duration with each exacerbation. What the health system does not do well is 1) provide early intervention supports to allow them to proactively manage their disability the rest of the time as well as allow them to maintain more normal and productive lives 2) assist with the significant out-of-pocket costs borne by sufferers to adhere to their treatment regime 3) help them to mitigate the debilitating consequences of cystic fibrosis.

Many adults with cystic fibrosis who are clinically stable and in the early stages of the condition visit cystic fibrosis clinics four times per year. That amounts to about 20 hours a year of contact with the healthcare system to manage an extremely complex condition.

The changes to the NDIS, which will be fully implemented by mid-2021, will deliver dramatic improvements to the quality of life for cystic fibrosis sufferers as at last, they will have the access to the services they need. These community-based services will complement the support provided by clinical care.

Some of the supports and services that will allow them to proactively manage their cystic fibrosis in the community and/or mitigate the debilitating effects of cystic fibrosis which are covered by the NDIS are extensive and the more common programs are listed below:

- Respiratory physiotherapy (community based)
- Exercise therapy/Personal trainers (community based)
- Respiratory supports (e.g., nebuliser and consumables, oxygen concentrators etc)
- Diabetic management supports
- Nutrition supports
- Support with domestic tasks/cleaning/garden maintenance
- Transport budget
- Continence supports
- Hearing aids, wheelchairs etc
- Mental health
- Financial management of NDIS plans.

Cystic fibrosis is a complex multi-organ condition that affects a person's ability to function in multiple ways (communication, mobility, getting along with people, life activities, participation in society, and even self-care). Multiple parts of a sufferer's body do not function properly, and they see multiple health professionals. To obtain medical evidence from all their treating specialists is daunting.

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Health professionals commonly involved in the treatment of cystic fibrosis include:

CF respiratory specialist

CF referred endocrinologist

CF referred Ear Nose and Throat specialist

CF referred gastroenterologist specialist

CF referred sleep medicine specialist

CF physiotherapist

CF referred psychologist

CF recommended exercise physiologist/personal trainer/therapeutic assistant

CF referred audiologist

CF referred fertility specialist

CF social worker

CF referred occupational therapist.

Most of the conversations about cystic fibrosis takes place with health care professionals in health care settings. Cystic fibrosis people know how to describe cystic fibrosis in medical terms but not in terms of functional impairment. This may contribute to assessors incorrectly viewing cystic fibrosis as a 'health condition' instead of a disability.

Significant stigma and discrimination still exist in society around the use of the term 'disability', with ingrained assumptions around what a disability is and looks like. Chronic illness related disabilities are invisible and still not commonly viewed as disabilities by the public. The cystic fibrosis community is very used to not getting the reasonable and necessary support required to help them participate in the community to their capacity, which consequently normalises a view that we do not even expect it or believe they are entitled/worthy of it.

While the community I represent welcomes the changes being made to NDIS accessibility, we are still concerned that assessors will not have the skills nor knowledge to understand the complexities of cystic fibrosis which may result in an inaccurate assessment and once again, people with cystic fibrosis - the most common life-shortening chronic illness in Australia today - will once again be left behind!