CYSTIC FIBROSIS Community Care
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# Cystic Fibrosis Community Care's response to the:

# Senate Community Affairs References Committee's Inquiry into the purpose, intent and adequacy of the Disability Support Pension

Cystic Fibrosis Community Care provides support to 1,697 adults and children living with cystic fibrosis plus their families, schools, colleagues and friends throughout New South Wales and Victoria.

Cystic fibrosis is the most common genetic life limiting condition in Australia. It is a lifelong and a degenerative condition that:

- Affects the functioning of multiple organs in the body
- Contributes to poor mental health and psycho-social function
- Can result in significant social isolation
- Can severely impact ability to work, study and independent living capacity.
- Can result in chronic extreme fatigue
- Requires a multi-disciplinary medical and allied health team and often multiple hospitalisations each year
- Over time results in significant reduction in physical health and function that requires assisted personal care and assistance with basic living skills. This includes reduced mobility, social connection and employment capacity, increased medical care and eventually palliative care.

Cystic fibrosis is often described as an invisible condition that manifests differently in every person that has cystic fibrosis.

Cystic Fibrosis Community Care would like to comment on the areas below as part of the Inquiry into the purpose, intent and adequacy of the Disability Support Pension (DSP)

**(b) The DSP eligibility criteria, assessment and determination, including the need for health assessments and medical evidence and the right to review and appeal;**

- Due to the variability of how each person living with cystic fibrosis experiences the condition there is often difficulty in describing the disability experienced by the individual. For example, a person with cystic fibrosis may be able to sit at a desk for 15hrs of work, but this would leave them exhausted to perform any other tasks in their daily life – such as self-care, 2+ hours of physiotherapy and social connection. Thus the assessment may determine the person ineligible for DSP on this basis. We ask that assessments for DSP take into consideration the needs of an individual – not just the hours of work requirement.

- In addition, the impact of cystic fibrosis on a person's ability to work can fluctuate over time. For example, cystic fibrosis often causes frequent lung infections and low lung function. This may impact a person's ability to participate in employment activities as they may be extremely fatigued due to their low lung function or need additional time to fit in additional treatments to maintain or recover from an exacerbation. People living with cystic fibrosis often require over 2 hours per day of medical treatments, including lung clearances and meeting extra dietary requirements just to remain 'well'. This time requirement can increase dramatically when they experience an exacerbation.
- The current DSP eligibility criteria, assessment and determination processes do not take the variability and episodic nature of exacerbations into consideration. Nor do they reflect the impact that working 15 hours a week has on the rest of their life. An individual may be able to work for 15 hours a week, however, they are so fatigued as a result those hours they require more sleep and are not able to participate in any other activities outside of work and treatments such as spending time with family, friends – they just work, do their treatments and sleep.
- Health and medical assessments conducted by the individual's clinical team, and/or, any medical evidence provided by the individual's clinical team, should be highly regarded and carry substantial weight in any eligibility assessment.

**(c) The impact of geography, age and other characteristics on the number of people receiving the DSP;**

- Treatment for cystic fibrosis is provided by specialised cystic fibrosis clinical teams at designated hospitals in capital cities. For example, there are two hospitals in Melbourne who provide care to the adult cystic fibrosis community. Living in a remote or regional area provides an extra financial burden on people with cystic fibrosis – as frequent trips to the clinics incur the considerable expense of accommodation, travel and time.
- This increased time and cost required to access specialist treatment and support can impact on a person's ability to work as they may require additional time spent traveling to and from treatment and appointments. They may also delay seeking treatment due the impact of travel which impacts on their health and well-being.

**(d) The impact of the DSP on a disabled person's ability to find long term, sustainable and appropriate, employment within the open labour market;**

- The current average life expectancy of a person living with cystic fibrosis is 42yrs.
- Cystic fibrosis is a progressive condition and a person's health will decline over time. As a result, as a person living with cystic fibrosis ages, their capacity to participate in employment decreases as their health declines. This is directly related to lung function, liver and pancreatic function, osteoporosis and mental health concerns associated with their condition and increased exacerbations and associated increased hospital treatments.
- The DSP is essential to providing financial support and security to people in the later stages of their life with cystic fibrosis.

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**(e) The capacity of the DSP to support persons with disabilities, chronic conditions and ill health, including its capacity to facilitate and support labour market participation where appropriate;**

- Cystic fibrosis affects each person differently. Some people experience a low level of impact on their work/ study/ independent living and social access. Other people have a heavy load of physical and mental health disabilities associated with their cystic fibrosis which means that they are unable to work.
- However, cystic fibrosis is a progressive condition that will increasingly impact a person's health and well-being and ability to participate in work over time.
- In addition, due to the increased impact that common respiratory infections (such as the common cold, the 'flu) and now COVID-19, can have on people with living with cystic fibrosis, their specialist clinics may recommend they avoid high risk environments where these infections may be caught. This may include public transport, schools and venues where the risk of airborne and surface cross infection may occur. This can limit employment opportunities in their area.
- People with cystic fibrosis may be required to have regular hospitalisations throughout the year, which disrupt employment. It is not uncommon for people living with cystic fibrosis to spend up 8 weeks a year in hospital receiving treatments. This exceeds all annual and sick leave allowances for an employee. Due to health issues, many people living with cystic fibrosis are working at their full capacity in part time work. Many people with cystic fibrosis may also need Hospital In The Home services after an inpatient stay – increasing the time that they are excluded from employment activities. This exhausts all leave entitlements.
- We ask that consideration of an extension to the DSP model to provide supplement payments to people who have used all their personal and annual leave for treatments and need to take leave without pay?

**(g) The adequacy of the DSP and whether it allows people to maintain an acceptable standard of living in line with community expectations;**

- The DSP is not adequate and does not allow people living with cystic fibrosis to maintain and acceptable standard of living due to the financial burden of living with this condition.
- The additional costs required for medications, physiotherapy equipment, supplements, additional dietary demands, and travel to and from hospitals and clinics and specialist appointments add an additional financial burden for people living with cystic fibrosis. Other programs such as the Pharmaceutical Benefits Scheme Safety Net program, Health Care Cards, and Patient Transport Schemes can assist to reduce some of the costs, however, they do not offset all costs and not everyone has access to these schemes. Many people rely on not-for-profit organisations, such as ourselves, to help with some of these additional essential expenses.

**(h) The appropriateness of current arrangements for supporting disabled people experiencing insecure employment, inconsistent employment, precarious hours in the workforce; and inequitable workplace practices;**

- People living with cystic fibrosis require workplaces that are very flexible with hours or work, planned and unplanned leave, environmental adjustments and workplace culture to reduce the risk to the person's health.

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We ask that consideration be given to an extension to the DSP model to provide supplement payments to people who have used all their personal and annual leave for treatments and need to take leave without pay?

**(i) The economic benefits of improved income support payments and supports for persons with disabilities, their immediate households and broader support services and networks;**

- The financial burden of living with cystic fibrosis is significant. Examples of some of the extra costs people living with cystic fibrosis may incur above regular every living expenses include:
  - Non PBS covered prescribed medications
  - Medical supplies (dressings for PEG and PIC lines)
  - Dietary supplements and specialist dietary requirements needed to improve nutrient uptake in diet
  - Continence products
  - Hospital car parking
  - Physiotherapy and medical equipment and telehealth devices such as nebulisers, oxygen concentrators, BiPAP machines, spirometers
- Currently, DSP income support payments do not come close to covering the extra financial burden of these expenses. It is common for people to seek emergency financial and material aid support to supplement the shortfall in DSP payments or have to make decisions about what essential treatments they can afford.
- Having a DSP income support payment that better meets the actual financial cost of living with cystic fibrosis would provide benefits to the person living with cystic fibrosis and their family through:
  - Relieving the stress and worry of having to decide which essential treatments they can afford this fortnight.
  - Being able to spend more time with their family and friends and taking care of their own well-being rather than focused on how they can afford to pay their next treatment bill or put petrol in their car or buy enough groceries.
- In addition, as a result of people being able to afford their treatments and take care of their health and well-being and experience less exacerbations, they may require less hospitalisations and reduced need on the health care system in the short and long term.

**(j) The relative merits of alternative investments in other programs to improve the standard of living of persons with disabilities;**

- There is substantial investment into the NDIS, however, this is not suitable for everyone. Cystic fibrosis is not listed as a condition covered by the National Disability Insurance Scheme (NDIS). The few people living with cystic fibrosis who have successfully accessed support through the NDIS have done so as they have a comorbidity of another conditions – such as psycho-social disability. This means that they have a double disadvantaged in their access to supports when their functional disability in only associated with cystic fibrosis. Therefore, more investment is required into the DSP to increase the rate and provide more specialised support that is tailored to the specific needs of an individual's condition and the associated costs.