

**Cystic Fibrosis Australia Advocacy
National Disability Insurance Scheme
October 2020**



Introduction	<p>The Cystic Fibrosis (CF) Federation of patient organisations and the Cystic Fibrosis community recently prepared submissions for the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) requesting that cystic fibrosis (CF) be included as a disability type in the NDIS.</p> <p>We welcomed the opportunity and it is pleasing that there is an appetite for inclusion and change. It is important that people with rare diseases and conditions where there is high and unmet need are equitably supported.</p> <p>The Cystic Fibrosis (CF) Community is collectively an active and forceful advocate for disability support equity and we believe it is fair that people with CF receive the same support as other Australians with the same challenges.</p> <p>The CF Community has a wealth of knowledge and real-life experiences and we are very happy to share these with The Minister for the NDIS Anne Rushton, NDIA personnel and the media to benefit people with CF in desperate need.</p>
Background	<p><u>Cystic Fibrosis Federation</u></p> <p>The Cystic Fibrosis Federation supports the broad cystic fibrosis (CF) community through Advocacy, Research, Clinical Improvement and Service Delivery. We are committed to improving clinical practice and patient outcomes with the aim of extending life expectancy to 50 years by 2025.</p> <p>Every four days a baby is born in Australia with CF and more than one million Australians are carriers of cystic fibrosis.</p> <p>The CF Federation advocates for equitable disability and health supports for people with CF to fulfil our mission to enhance the quality of life of people affected by CF. The Federation strongly believe that Australia has one of the best social service and support systems in the world.</p>

	<p>People with CF should also have access to the NDIS as the disease is extremely debilitating and external care supports for the most basic tasks are urgently needed. For further information please visit our website at https://www.cysticfibrosis.org.au/</p> <p>CF Hub</p> <p>The Australian CF Hub is an independent community group made up exclusively of Australian adults with cystic fibrosis (CF). We interact online as face to face interactions are deemed high risk due to potential for cross-infection with dangerous respiratory infections. We provide informal peer support, facilitate knowledge sharing, and are involved in CF advocacy.</p> <p>Our mission is to connect and empower adults living with CF so that all people with CF have the support, knowledge, and confidence to manage their disability well, pursue their goals, and participate fully in all aspects of life.</p> <p>While the Australian CF Hub is not affiliated with any organisation we do work collaboratively with our CF organisations and CF clinics for the benefit of all Australians living with CF.</p>
<p>NDIS Access Issues</p>	<p>1. <i>Cystic fibrosis should be added to the list of disability types eligible for NDIS supports (List A)</i></p> <p>Supporting Evidence</p> <ol style="list-style-type: none"> 1. In October 2019 health related supports were included in the NDIS and this was a great step forward and recognition of the gaps in health and disability related supports. 2. People with CF live with permanent and every increasing functional impairment and they need NDIS funding to live a life with value and inclusion 3. When looking at the NDIS Eligibility List many people with CF score highly. They need <ol style="list-style-type: none"> a. Support from a person because of permanent and significant disability b. Specialist equipment because of permanent and significant disability c. Support now to reduce further need d. Support for a permanent disability (lifelong impact) e. Support for a significant disability (substantial impact on daily activities) f. Early intervention to reduce the impact of CF and build skills and independence

2. *There are gaps between health related supports and eligibility for NDIS funded supports especially for people with cystic fibrosis.*

Supporting Evidence

1. In short people with CF need NDIS funding to
 - a. Help them in their daily life
 - b. Participate in community
 - c. Assist them to reach their goals
 - d. Support rural, regional and remote consumers who don't live near their CF Care Centre with physio and mental health
 - e. Stay as well as possible and remain in control of their lives.
2. The health system does NOT
 - a. provide early intervention supports to allow People with CF to proactively manage their disability the rest of the time as well as allow them to maintain more normal and productive lives
 - b. assist with the significant out-of-pocket costs borne by people with CF to adhere to their treatment regime
 - c. help people with CF mitigate the debilitating consequences of CF.

3. *Not all NDIS assessors are not knowledgeable about cystic fibrosis and therefore the assessments process is inequitable. A Trained Assessor Unit with a solid understanding of rare diseases like cystic fibrosis should be established.*

Supporting Evidence

1. The level of ability (or disability) that CF creates varies greatly from person to person
2. CF is an invisible disease that manifests in a variety of ways
 - a. chronic and extreme fatigue from fighting infection and insufficient sleep due to breathing difficulties/coughing at night
 - b. a burdensome disease that requires people to spend hours on time-consuming but essential treatments such as airway clearance, inhaled medications via nebulisers and between 30 and 80 pills a day plus numerous medications; exercise therapy; and regular nutrition breaks.
 - c. Currently people with CF only qualify for NDIS access when they develop severe lung disease i.e. on the transplant list
3. In more than 50 documented cases NDIA assessors have demonstrated a concerning lack of understanding of CF, the disease and the impact it has on the patients and their families.

4. Assessors view CF as a treatable disease, which implies a cure. There is no cure for cystic fibrosis.
5. The available treatments and therapies only serve to slow the speed of this degenerative disease. People with CF who receive a lung transplant must closely follow an extremely complicated medication regime and also be closely monitored at tertiary hospitals for the rest of their lives.
6. CF still affects the whole body and patients need to manage all the other comorbidities like diabetes, CF liver disease, colon cancer and pancreatic insufficiency.
7. CF is a permanent, incurable, degenerative and complex multi-organ condition that affects a person's ability to function in multiple ways
 - a. Communication – laughing, talking and hearing loss
 - b. Mobility and accessing public transport and exercise
 - c. Getting along with people and community connection
 - d. Life activities including household chores, meal preparation and work
 - e. Fight infection and maintain healthy weight
 - f. Peg feeds and home IV antibiotics
 - g. Living independently and participation in society and
 - h. Sleep apnea and inability to sleep, selfcare and personal hygiene tasks.
8. Health professionals involved in CF care and treatment include
 - a. CF respiratory specialist
 - b. CF referred endocrinologist
 - c. CF referred Ear Nose and Throat specialist
 - d. CF referred gastroenterologist specialist
 - e. CF referred sleep medicine specialist
 - f. CF physiotherapist
 - g. CF referred psychologist
 - h. CF recommended exercise physiologist/personal trainer/therapeutic assistant
 - i. CF referred audiologist
 - j. CF referred fertility specialist
 - k. CF social worker
 - l. CF dietician
 - m. CF referred occupational therapist

Key Messages	<p>The Cystic Fibrosis Community is asking for three amendments to the current NDIS</p> <ol style="list-style-type: none"> 1. Add cystic fibrosis to the NDIS List A 2. Close the gap between health-related supports and eligibility for NDIS funded supports 3. Establish a Trained Assessor Unit to ensure equitable assessments for people with rare disease like cystic fibrosis.
Who	<p>This is a collaborate advocacy project between</p> <ul style="list-style-type: none"> • the CF community • CF Hub • Cystic Fibrosis State and Territory organisations and • Cystic Fibrosis Australia <p>The advocacy resources developed by Cystic Fibrosis Australia used the submissions to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) by Cystic Fibrosis South Australia and the CF Hub.</p>
What	<p>What could people with CF do with NDIS funding</p> <p>NDIS could benefit people with CF is a multitude of ways ...</p> <ul style="list-style-type: none"> • Respiratory physiotherapy (Community based) • Exercise therapy/Personal trainers (Community based) • Respiratory supports (e.g. nebuliser and consumables) • Diabetic management supports • Nutrition supports • Support with domestic tasks/cleaning/garden maintenance

	<ul style="list-style-type: none"> • Transport budget • Continence supports • Hearing aids
<p>When</p>	<p>Key Dates and Activities</p> <p><u>October</u></p> <ol style="list-style-type: none"> 1. Attempt to book meetings with relevant MPs and Senators from both sides of the House 2. Attempt to book meetings with NDIS policy advisors 3. Contact Media - Launch 4. Attend meetings with relevant MPs and Senators from both sides of the House 5. Activate social media 6. CFA Communique - Launch 7. Begin consumer advocacy at the local level. Community members are encouraged to <ol style="list-style-type: none"> a. Contact local MPs and Senators b. Contact local media c. Write their personal case study for sharing with politicians, media and on social media (deidentified) <p><u>November</u></p> <ol style="list-style-type: none"> 1. Attend meetings (Zoom and F2F) with relevant MPs and Senators from both sides of the House 2. Attend meetings (Zoom) with NDIS policy advisors 8. Contact Media – Status and Talking Heads 9. Continue social media 10. CFA Communique – Activate Community 11. Continue consumer advocacy at the local level. Community members are encouraged to <ol style="list-style-type: none"> a. Contact local MPs and Senators b. Contact local media c. Write their personal case study for sharing with politicians, media and on social media (deidentified)

	<p><u>December</u></p> <ol style="list-style-type: none"> 1. Continue meetings (Zoom and F2F) with relevant MPs and Senators from both sides of the House if necessary 2. Continue to attend meetings (Zoom) with NDIS policy advisors if necessary 3. Contact Media – Update and Case Studies 4. Continue social media 5. CFA Communique - Update 6. Consumer Petition for delivery to Minister, Shadow Minister and head of NDIA as a Christmas Gift. <p><u>January, February and March 2021 – Activities will depend on NDIS inclusion status and will be drafted in December 2020</u></p>
<p>How</p>	<p>Cystic Fibrosis Australia</p> <ul style="list-style-type: none"> • will develop a public portal on their website • hold a Consumer Connect session for CF CAN advocacy training • Contact Federal Politicians involved in NDIS policy • Contact NDIA personal to present ‘eligibility issues’. <p>Consumers and CF state and territory organisations will be able to access these resources to create local campaigns involving politicians and media.</p>
<p>Why</p>	<p>Why should people with CF receive NDIS funding</p> <p>The health system supports the medical needs of people with CF however it does not</p> <ul style="list-style-type: none"> • provide early intervention supports to allow people with CF to proactively manage their disability the rest of the time as well as allow us to maintain more normal and productive lives

	<ul style="list-style-type: none"> • assist with the significant out-of-pocket costs borne by people with CF to adhere to our treatment regime • help people with CF to mitigate the debilitating consequences of CF. <p>Managing cystic fibrosis is extremely challenging and time consuming. CF is often an invisible disease but it impacts every aspect of ones life and the lives of family members.</p> <p>Mental health and social isolation are considerable barriers that many people with CF face. This also leads to depression and anxiety in the family unit.</p> <p>People with CF experience continually diminished functional capacity and this increases the treatment burden.</p> <p>With access to appropriate NDIS supports and services people with CF could better manage their disease and the treatment regime, resulting in better quality of life and reduced disability in the years to come.</p> <p>NDIS supports will give people living with CF more independence to participate in and contribute to society. This means spending less time in hospital, being able to work more, being able to spend more quality time with their families and friends and participate more in their communities.</p> <p>Significant stigma and discrimination still exists 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.</p> <p>Many people with CF try so hard to live a regular life and not be limited by CF that it’s hard for them to acknowledge they have a disability.</p>
<p>Secondary Messages</p>	<ul style="list-style-type: none"> • Let’s not forget a key tenet of our national anthem ... With courage let us all combine to Advance Australia Fair • And when it comes to rare disease ... you can’t equate “rare” or “small numbers” with “insignificant” • Many of the CF community (parents, siblings, extended family, medical specialists and allied health workers) are taxpayers and they have the right to expect the people with CF that they are connected to benefit from Government funded programs.

Outcomes	<ol style="list-style-type: none"> 1. Equitable patient centric NDIS eligibility 2. Families and unpaid carers can re-enter the workforce 3. Australian's living with a rare diseases (like CF) are not ignored or excluded from Government funded supports 4. People with CF can live with dignity and purpose 5. Suffering is reduced and lives are saved.
Recommendation	<p>The Cystic Fibrosis Community recommends that</p> <ol style="list-style-type: none"> 1. Cystic fibrosis be added to the NDIS List A 2. The gap between health-related supports and eligibility for NDIS funded supports be closed 3. An assessor with knowledge about cystic fibrosis reviews CF NDIS applications.
MPs & Senators	To be drafted when Case Studies are in and campaign is about to begin.
Media Releases for Local Media and use by the CF Community	To be drafted when Case Studies are in and campaign is about to begin.
Social Media	To be drafted when Case Studies are in and campaign is about to begin.
NDIA / NDIS management	To be drafted when Case Studies are in and campaign is about to begin.

Case Study

1. Name (to be kept confidential unless otherwise advised) -
2. Post Code (to be kept confidential unless otherwise advised) -
3. CF Centre and State (to be kept confidential unless otherwise advised) –
4. CF Mutations (to be kept confidential unless otherwise advised) –
5. Health Status (to be kept confidential unless otherwise advised) – FEV1, BMI, PI, CFRD, CFLD - (approximations)
6. Mental Health Status (to be kept confidential unless otherwise advised) – Depression, anxiety, isolation
7. Work Status and sector – FT/PT
8. Qualifications – School and tertiary –
9. What was your NDIS experience in no more than 400 words -
10. What I can do now -
11. With NDIS support what I will be able to do -
12. How will NDIS funding benefit my family -
13. What will you spend your NDIS funding on – supports and treatments -
14. How much do these supports and treatments (Q, 13) currently cost you -
15. Photo (not mandatory)

Agreement to be signed by all Case Study subject as to what can be revealed (from 15 points above) and with whom it can be shared (media, website/social media, CFA Communiques, CF Hub emails, politicians, community and CF Centres).

6 October 2020