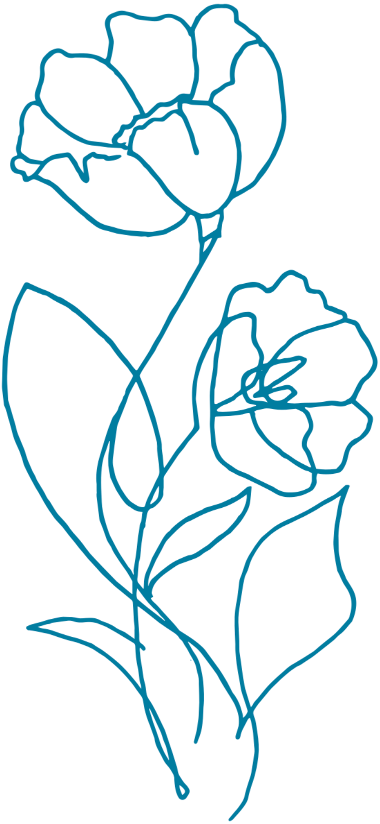
CYSTIC
FIBROSIS NZ

MANAGING DAILY LIFE WITH CYSTIC FIBROSIS



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Cover artwork & illustrations throughout by CFNZ's very own Lizzie Mackay - Communications and Public Awareness Manager


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TIPS AND ADVICE FROM KIWI ADULTS, SOCIAL WORKERS AND OTHER HEALTH PROFESSIONALS

Adult life is busy. And adult life with CF is even busier. It can be challenging, and annoying, to find time to fit in university, work, family – generally having a life – with all the extras CF entails.

“Try and get the hard stuff done as soon as possible in the morning, as once the day gets going it’s tricky to fit boring or extra treatments in.”

“I always make sure doing my treatment is the first thing I do each day. I think of it as, if I get this done now, I get the rest of the day to work and see friends without having nebulisers hanging over me.”

“Try to get decent rest; waking up tired is so un-motivating and managing CF routines feels harder.”

“Chuck on a podcast or read something interesting when doing nebs to help reward or distract you.”

“Do your acapella when driving if you have a commute, even if it’s not as good as being focused solely on it at least it’s getting done.”

“I have a pill box that has four compartments for each day. For the first few years post-transplant, I filled my pill box each week which was hugely helpful in remembering and learning all the new and changing medication I was on. I still use this pill box when I go away as it makes life a little easier.”

“Don’t let CF be an excuse. As a child I used it all the time! As an adult, consider it a challenge and almost a duty to everyone else with CF who’s struggling to try and push yourself a little harder sometimes.”

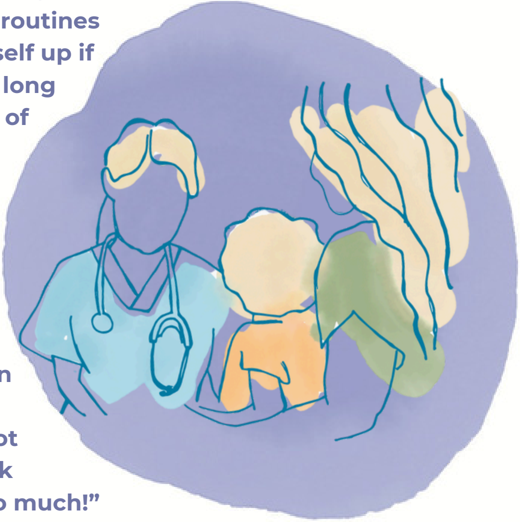
"Make time to do activities that takes your mind of CF, such as painting, reading, playing playstation or listening to music."

"I have my 'basket of tricks' ie. medication, in my bedside table. The trays are all organised with my different meds, and I keep the rest of my "stock" in the cupboard and replenish when necessary. This means everything is in the same place and easy to find, in case something happens and someone has to come and grab them in an emergency."

> **Keep in touch with your CF team, don't let chest infections creep up and get serious-avoid unplanned admissions by doing this and feel more control. Text your CF nurse, sort out that sputum sample, stay on their radar. Follow up on results all the time.**

"Knowing I'm most productive in the mornings, I make sure my morning routine covers all the essential activities to keep me well – it's when I exercise, take my meds, do my nebuliser and physio. While it means an early start, it sets me up for the day and I know by the end of the day I'm going to be too tired to get the same value out of exercising and other treatment."

"While it's important to have a routine, it's just as important to recognise that routines get disrupted and not to beat yourself up if you miss completing something as long as it doesn't happen too often. One of the most valuable things I've learned is to listen to my body. It's very easy to over commit to activities and events, but you need to listen to your body and acknowledge when you're feeling tired and need to rest. Friends and family are very understanding when I've had to pull out of something because I feel too tired, while it's not nice to miss out it beats getting sick because you've pushed yourself too much!"



"If you have a hospital admission, get good pillows and have some nice hospital pajamas. Even as an adult, take in a blanket or some comforting things to hospital and keep your spirits up however you can."

"Life with CF is hard, as, for those with severe CF, our career paths don't always follow a linear progression. We have to constantly bounce through the changes and bounce in directions we didn't think we would bounce in. It's like being on stilts and then finding out they come with springs, not easy to steer. Additionally, we get asked at every clinic, about work, what we do, and if we remember previous answers given in begone years it can feel a lot like failure. But it's not. Even for people without CF, no one's life goes exactly how they planned it and eventually a curve comes. Like the 2017 Jeep Compass ad, we are constantly recalculating, changing course and re-defining what we find our identity in. For example, finding identity in the acceptance and fun of good friends. Finding identity in being a partner, mother or father, uncle or aunty. For those who believe in God, believing God sees you as valuable.

Finding identity in who you are, that you care for others that you are kind. Currently, CF and life are not in our control, and I always tell myself, I did the best I could with where my headspace was at the time."

Having CF doesn't mean not starting something. As someone close to me always used to say, aim for the moon and at least you'll at least land among the stars. All our experiences and stuff we do either works out or adds to our experiences, that make us who we are. I don't want people with CF to be scared to pursue a degree or something like that, especially with the treatments coming out like Trikafta. Also making a dream and pursuing it is part of being human, so make some dreams."

TIPS FROM SOCIAL WORKERS AND OTHER HEALTH PROFESSIONALS

“Learn to prioritise what’s important and ask for help when you need it – don’t wait until you’re sick.”

“Put your CF nurse’s contact information in your phone so you can easily contact them when you need to.”

“Talk with your fieldworker or CF team if you’re unable to work as much as you like. You may be entitled to a disability allowance or your CF doctor can sign a Working Capacity medical certificate to help WINZ understand how affects your life and any benefits you may qualify for.”

“Try to create a routine you can follow each week. Review it at the start of each week and adjust to what you and your family have on. It can help if you put reminders on your phone or electronic device for everything you need to do, including any appointments you have. Using a calendar or organiser can help.”

TOP TIP

“If you can, save a small amount of money - $5 or $10 a week – to cover any admissions, unpaid sick leave, extra CF expenses.”

Let your CF team know if you're finding it hard to complete your daily treatments. They may have other suggestions to help or can streamline your management.

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Review it at the start of each week and adjust to what you and your family have on. It can help if you put reminders on your phone or electronic device for everything you need to do, including any appointments you have. Using a calendar or organiser can help."

"Link in your treatments with fun activities, such as during watching TV or listening to music to stay motivated."

"Working flexible hours can be a big help."

CONNECTING WITH OTHER PEOPLE WITH CF

You can join one of our Facebook groups if you're keen to connect with other people with CF

CFNZ adults (private group): facebook.com/groups/135748981173/

BreatheEasyCFNZ (private group pre and post-transplant):

facebook.com/groups/707882349311590

Cystic Fibrosis New Zealand (public page): facebook.com/
Cystic Fibrosis NZ

Access for Aotearoa (public group focuses on precision medicines):
facebook.com/groups/AccessForAotearoa

IF YOU'D LIKE TO KNOW MORE

Cystic Fibrosis New Zealand (CFNZ) is a charity dedicated to supporting New Zealanders and their families who have CF. If you'd like to know more about CF visit our website www.cfnz.org.nz for up-to-date information. You can also contact our national branch team on 0800 651 122 or by emailing info@cfnz.org.nz

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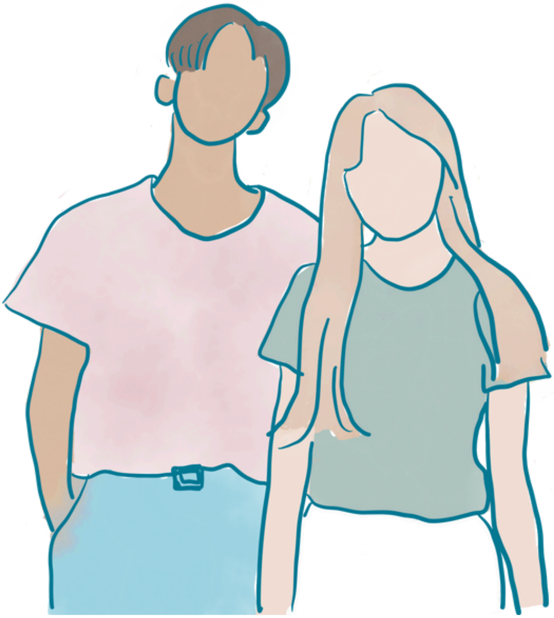


Disclaimer

This publication has been written as a general guide for adults with cystic fibrosis in New Zealand.

While Cystic Fibrosis New Zealand (CFNZ) has consulted with healthcare professionals and adults with cystic fibrosis to ensure the information is accurate, it does not substitute specialist medical and employment advice. CFNZ will not be held liable for inaccuracies or omissions.

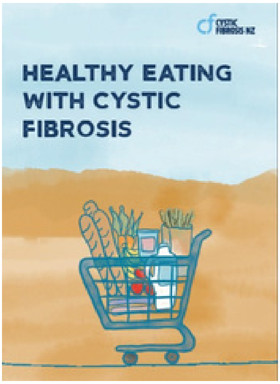
DOCUMENTS IN THE ADULT GUIDE SET:

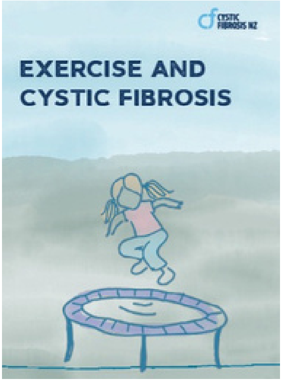
Click on icon to below to view other resources.

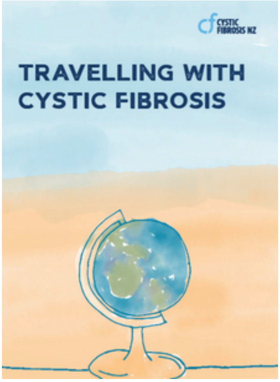

SUPPORT FROM CYSTIC FIBROSIS NEW ZEALAND


TRANSITIONING FROM CHILD TO ADULT SERVICES


MENTAL HEALTH AND WELLBEING

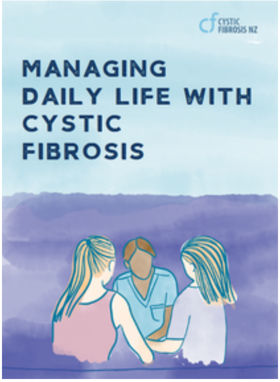

HEALTHY EATING WITH CYSTIC FIBROSIS


EXERCISE AND CYSTIC FIBROSIS


TRAVELLING WITH CYSTIC FIBROSIS


FERTILITY AND SEXUAL HEALTH


FAMILY PLANNING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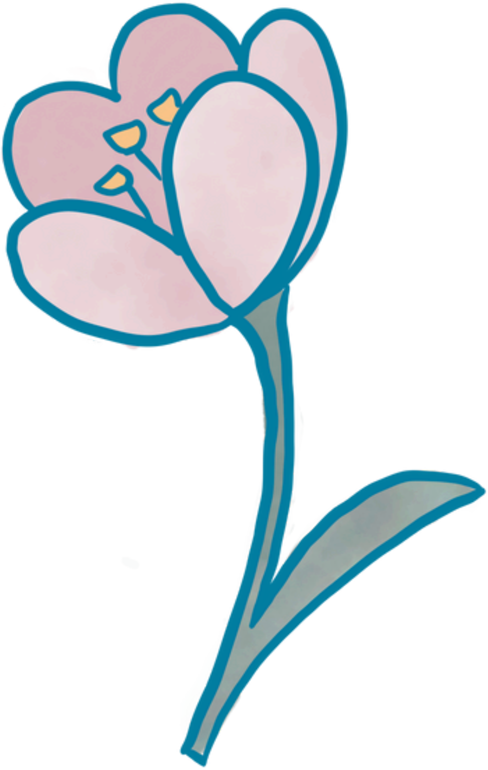

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