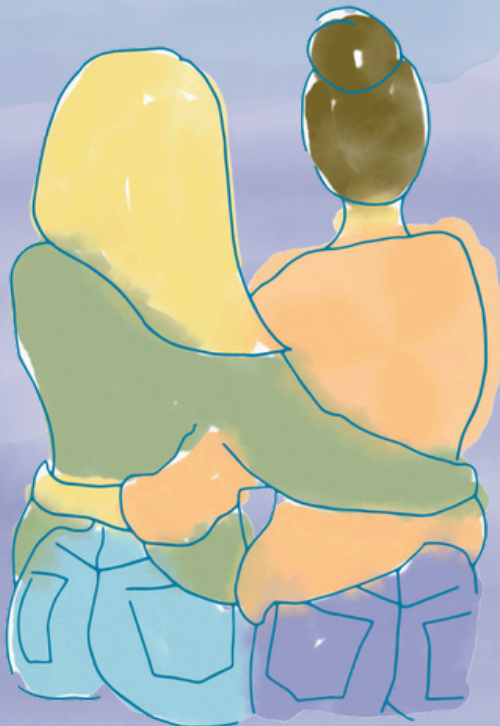
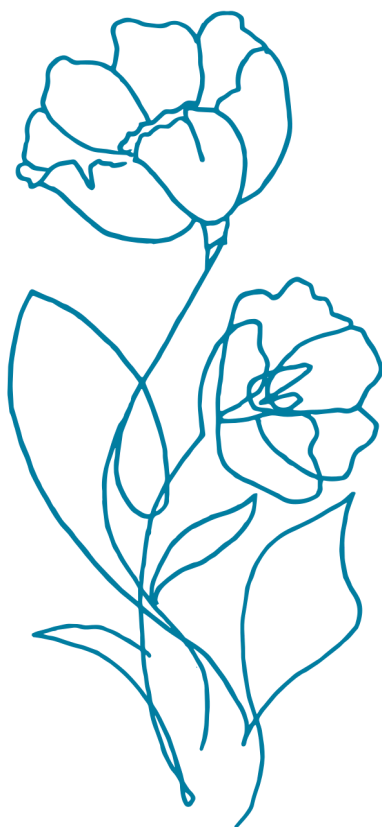


TRANSITIONING FROM CHILD TO ADULT SERVICES





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

Contact:

T: 09 308 9161

E: admin@cfnz.org.nz

Fundraising:

T: 09 308 9161

E: fundraising@cfnz.org.nz



TRANSITIONING FROM CHILD TO ADULT SERVICES

SOME KIWI ADULTS WITH CF HAVE DESCRIBED THEIR TIME MOVING FROM CHILD TO ADULT SERVICES AS CHALLENGING, AND A BIT OF A SHOCK. OUR HOPE IS THIS TIME FOR YOU GOES AS SMOOTHLY AS POSSIBLE AND YOU'LL FEEL SUPPORTED BY YOUR CF TEAM AND CFNZ FIELDWORKER.

This section includes comments and tips from adults about how they managed their transition. There's also advice from our fieldworkers and adult CF nurses.

Transitioning is a process. Your CF team and fieldworkers will work with you to help you manage some of the expectations of adult services, such as managing your own care and appointments and how to take a more active role in your care.

Anything new and different can be a challenge – for you and your family. Your adult CF care team may encourage you to attend clinic on your own to help encourage more independence, but you can bring a support person with you to clinic if you want and need to.

Your CFNZ fieldworker will stay the same and is a good support person to have during transition. You may like to ask them to attend some initial clinic appointments with you, as this can be a nice transition from parent to independent visits.

HOW YOU CAN HELP PREPARE TO MOVE TO ADULT SERVICES

Transitioning from child to adult services is the perfect time to consolidate your knowledge about CF and understand how to keep yourself well.

Think about if you can answer these questions. The more you

understand about F and how it affects you, the more you are an advocate for yourself with your F team.

General knowledge about cystic fibrosis

What do you know about CF?

How does CF affect your health?

Do you know your genetic mutations?

Do you know what all your medications are for? What happens if you don't take them?

How do you know you're becoming unwell and what do you do?

Who do you contact from the CF team if you're unwell?
How do you contact them?

What's your FEV1 and why is it important?



Support with daily treatments

Who do you contact if you find areas of your treatment challenging?

How do you contact the dietitian if you have issues with weight management?

How do you contact the physio for support or advice?

How do you contact the nurse if you're feeling unwell or need advice?



Managing prescriptions

Who do you contact for a repeat prescription, and how do you contact them?

What do you do if you run out of medication?

Do you know how to contact your GP?

Do the CF team know the pharmacy you go to?

Equipment

Who do you contact if you need nebulising equipment or your equipment breaks down?

During your admission

What antibiotics are you on and can the timing of them be planned around when you sleep and other daily activities?

What time are the ward rounds?

Does the ward provide CF snacks during your admission?

Which specialists are you under this admission?

How often should I get weighed?

Is it possible to do IV antibiotics at home? If so, how is this initiated?



TRANSITIONING TIPS FROM ADULTS

"I felt nervous a couple of times to approach my adult nurse. I even had the paed's nurse ring her on my behalf to tell her I was unwell and needed a hospital admission. As time went by, I started enjoying the decisions I got to make and the respect I was shown for managing my treatment well."

"I learned the hard way how important it is to keep track of my medications and to ask in advance for prescriptions to be arranged. I feel proud about accomplishing it and I'm generally more organised in other aspects too."

"I was very excited to move to the adult ward as I could enjoy the quietness and facilities my own room had to offer. I got recognition as an individual and enjoyed the options available to me about my treatment."

plan and the freedom I felt in planning with the team.”

“Ask for an email address and phone number of the person who is your first point of contact if you need to ask a question or if you’re concerned about your health.”

“A huge emphasis was put on transitioning from Starship to Auckland Hospital, so the process started early to prepare me for the change of team and hospital routine. At first I didn’t realise why it was such a big deal but quickly learnt that moving teams meant moving out of my comfort zone, not being around doctors and nurses who I’d known and who knew me for the past 17 years. A few things that I did that helped before moving to adults were staying the night by myself in hospital during one of my admissions since parents can’t stay when you’re admitted under the adult team, doing lung function without Mum or Dad being in the room and learning what FEV1 and FVC meant, seeing the consultant at clinic without Mum or Dad and being in charge of my medication ‘stocktake’ at home so I knew what scripts I needed each clinic.”

“Write down questions to ask at your next clinic visit. It can also keep to keep a diary of any issues so you’re one step ahead when asked ‘how often does ____ happen?’, ‘when was the last time ____ happened?’, ‘what time of the day does ____ happen?’”

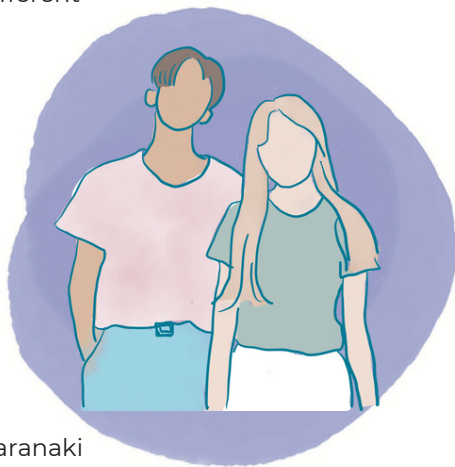
CHANGING CF TEAMS IF YOU MOVE TO ANOTHER AREA

You may need to change CF teams if you move to another town or city serviced by a different district health board. Depending on where you move, your CFNZ fieldworker may remain the same as they cover different areas than DHB boundaries.

Northern fieldworker – Auckland and Northland

Upper Central fieldworker – Waikato and Bay of Plenty and Lake s

Central fieldworker – Wellington, Hawke’s Bay, Central Districts and Taranaki



Southern fieldworker – All of the South Island

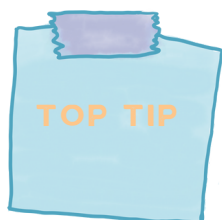
Remember to register with a new GP and pharmacy in your area.

It's a personal decision whether you change CF teams if you move to a different city to attend university. You'll need to self-fund travel back to your original town or city for clinic and hospital appointments if you stay under the care of your original CF team. Discuss this with the CF team as they'll need to write referrals to a new team if you change teams.

Many adults decide to change CF teams if they're away from home for some time. Talk with your CF team well in advance of moving so they can help transfer care, including providing a handover to your new team. Ensure you have enough supplies of medications and equipment.

Take all your equipment and medications with you when you move. Fieldworkers don't have supplies of medication or equipment and it can take time to arrange an appointment with your new team and to organise what you need.

"When I moved towns, funding was different and the team didn't have as many specialists. Luckily my old team was super supportive over the phone or text if I had any questions."



"Be prepared to increase your self-advocacy again as things can get pretty comfortable with the same team and the new team may do things differently. But also consider the opportunities and new perspectives a new team may offer."

In my experience, I was able to maintain contact with the old team as well, for annual reviews and just as a backstop adjusting to some differences in prescribing meds. Consider checking out with your old team if they have the resources for you to keep in touch while transitioning, if that's what you want."

“What I’ve found really helpful when I moved overseas is to reach out to the new team in advance and let them know you’re coming and ask them what the process is for getting an appointment. Each country has their own health system to navigate and you may need a referral to the CF team before you can get an appointment with them, and this might mean going to a GP first. Ask your doctor for a letter detailing your current medications, allergies, lung function results etc, to give your new CF team so they can get a baseline. This is particularly helpful if you’re moving overseas as they don’t have access to the NZ databases.”

TRANSITIONING TIPS FROM OUR FIELDWORKERS

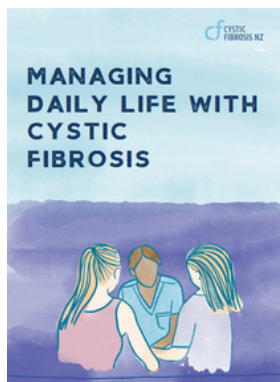
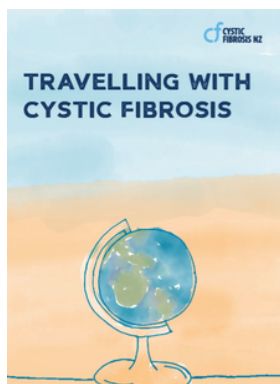
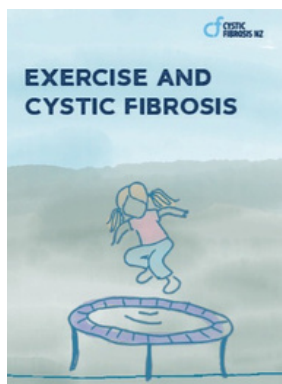
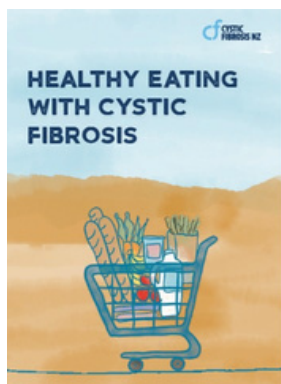
“It can be hard moving from a team you’ve known for up to 16 years. Adult services treat you differently – they take more of an advisory, hands off role. You’ll need to learn to become an advocate for yourself, so educate yourself about your CF.”

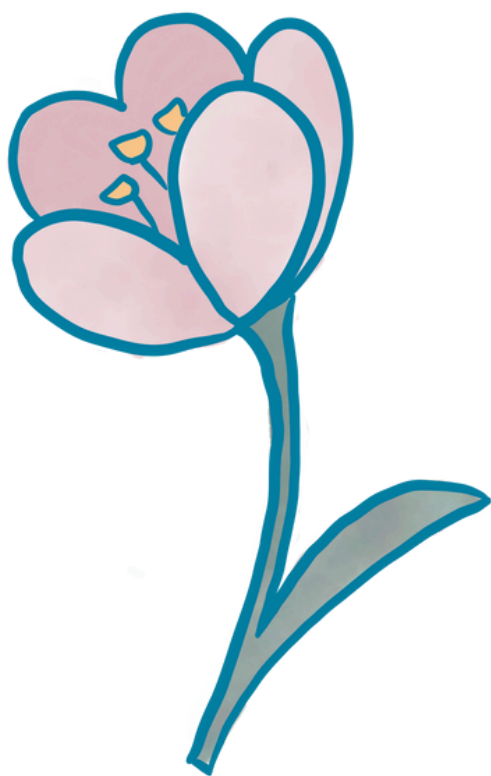
“It’s a good idea to start having 10-15 minutes of your appointment with your paediatric team by yourself from about age 14 so you get used to talking about your own care, especially sensitive topics such as bowel movements and more awkward conversations.”

“Whether you’re transitioning from child to adult services or a new CF team and hospital, your fieldworker can meet with you and give you a guided tour of the new hospital, including the clinic rooms and wards. This way you’ll be familiar with the environment before admission or clinic visit.”

DOCUMENTS IN THE ADULT GUIDE SET:


Click on icon to below to view other resources.





Published: October 2024
Cystic Fibrosis New Zealand

Contact Cystic Fibrosis New Zealand
0800 651 122 / info@cfnz.org.nz
64 Grafton Road, Grafton, Auckland 1010

A thick, dark blue horizontal line with a slightly wavy, hand-drawn appearance spans the width of the page near the bottom.