COVID-19: Your Care

Information for patients with Cystic Fibrosis

Thank you for your enquiry regarding Coronavirus (COVID-19).

Information is updated regularly and the Cystic Fibrosis Service is in communication with Alfred Health and Infectious Disease Experts to keep you up-to-date.

Frequently Asked Questions

Should I have the flu vaccination?
The Cystic Fibrosis Service recommends the flu vaccination to protect you in the coming winter flu season. This will not protect you against COVID-19. The flu vaccination can be accessed via your GP or local pharmacy. We suggest that you call ahead to confirm availability of the free vaccine. At this stage, we are not able to offer the flu vaccination in the outpatient setting, however, we will update you if the situation changes.

What do I do if I need a blood test?
If your CF doctor feels it is necessary for you to have a blood/ sputum/ urine test, we will post or email you a pathology slip. We encourage you to have the test performed at your local pathology centre approximately 1 week before your review with the CF team. Please email us to let us know when and where you had the tests done so that we are able to chase your results.

Should I come to my outpatient / HITH review clinic appointment?
Most of our CF clinic appointments are now being conducted via telehealth (video call). You will be contacted by our Clinic Coordinator prior to your appointment who will provide you with the web link as well as your appointment time. During your telehealth appointment you will see your usual CF team; including the doctor, dietitian and physio as well as our psychologist and social worker, if needed.

How can I monitor my health at home?
Anyone who has been given a Peak Flow Meter might find it useful to use that as a gauge for yourselves to track any big changes in your lungs. There are ongoing efforts to investigate the best option to measure lung function at home using a portable lung function machine (spirometer). These include a couple of models already being recommended by other CF Centres. Unfortunately, some devices on the market have been shown to be inaccurate or faulty.

It may also be useful to have a set of weight scales and a thermometer at home to help guide the CF team in making decisions about changes in your treatment. For some people, regular blood pressure checks are also required to help monitor the effect of some medications such as Orkambi® and Symdeko®. We encourage you discuss the need for blood pressure monitoring with your CF doctor.

Who should I contact if I have symptoms?
If you become unwell, please call the CF nurses on 0418 596 938 to discuss your symptoms and a treatment plan. The Alfred also has a COVID-19 screening clinic, the details of which can be accessed via the Alfred website. COVID-19 presents just like other colds or the flu, so it is important to be tested. If you become unwell after hours or on the weekend, please phone the Respiratory Registrar on-call via the Alfred switch board on 90762000.

Cystic Fibrosis Service
55 Commercial Road, Melbourne
VIC 3004
T 03 9076 2315
F 03 9076 8050
E cysticfibrosis@alfred.org.au
CF Nurses - 0418 596 938

We recommend that you seek information only from credible websites such as:

Alfred Health
www.alfredhealth.org.au

Victorian Department of Health and Human Services (DHHS)
dhhs.vic.gov.au/coronavirus

Australian Government
www.health.gov.au

Australian Smart Traveller
www.smartraveller.gov.au

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What happens if I need to come to hospital for an admission?

When you come in to the hospital, it is no longer necessary for you to go to ‘Admissions’. We would like you to minimise your movements around the hospital and head straight to your allocated ward to begin your treatment.

It is now a hospital requirement that anyone with respiratory symptoms be tested for COVID-19. The test involves 2 swabs, taken at different times, from the back of the throat and nose (in that order). This will take place once when you arrive to the ward. You will then be moved to a different ward, depending on the result of your swab.

The hospital has adequate PPE (Personal Protective Equipment) for staff and we are all trained in how and when to use it. The CF service are working closely with ward staff and the Hospital in the Home team to ensure you can get home as quickly and safely as possible.

What do I do if I need a script or medications?

Please check all of your medications and scripts and email us at cysticfibrosis@alfred.org.au with a list of what you need. Your email will then be sent to our pharmacy team who will call you to go through your medications. Our Pharmacist will be calling from a private number so please make sure you answer. Please allow 2 weeks between the time of your request and when you are likely to receive your script/medications. Alfred-only medications (medications that can only be dispensed from The Alfred) will be posted out to you. All other medications will need to be accessed via your local pharmacy.

What if I need to have my PORT accessed?

We are still able to accommodate outpatient appointments in our isolation clinic rooms. Please send us an email 1-2 weeks before your PORT flush is due so that we can arrange an appointment. We are currently exploring other options for our patients to have their PORTs accessed in the community.

What do I do if I need a medical letter?

Please email us at cysticfibrosis@alfred.org.au. We will be able to assist with a generic letter, however, if you require an individualised letter or document/s, we recommend that you book an appointment with your GP.

Can I get priority access to groceries?

Woolworths have a priority assistance request form you can login to via their website. Coles also have an online priority service which may require a code that can be accessed via CF Community Care. Send your full name and ‘The Alfred CF Service’ to robynp@cfa.org.au.
Nutrition

Can COVID-19 be transmitted by food or food packaging?
Currently, there is no evidence that COVID-19 can be transmitted through food. There is a useful summary of what is known about this question on the Food Standards Australia New Zealand website, listed below.


Food safety at home
With many of us going shopping less frequently and stocking up more at each shop, plus increased meal preparation or using leftovers, it’s a great time to check that routine everyday food safety practices are being used at home: while there is no evidence that COVID-19 can be transmitted by food, anyone can be at risk of other food-borne illnesses caused by contamination with bacteria due to poor food storage or handling. This website has some useful everyday advice about food safety and storage

Oral Nutrition Supplements and Enteral feeds

Supply
Currently, there are no major concerns with regards to product availability. As always, there are specific individual products or flavours that have a supply issue for a short period of time (this is “situation normal”). If we know that a certain product is out of stock when you contact us for an order, we can discuss an alternative product or flavour if needed.

Ordering & delivery
The process for ordering your enteral feed or nutritional supplements remains the same. Due to high demand, delivery times may be longer than usual. If you are regularly on enteral feeds or oral nutritional supplements, please ensure that you keep a close eye on your supply levels at home. We encourage you to contact us at least 10-14 days before your supply is due to run out.

Please contact us via email at cfdietitians@alfred.org.au or phone us on 9076 3063 to discuss your needs. In some instances, your dietitian may suggest a clinic or telehealth review to discuss your ongoing nutritional needs.
Managing stress and mental health

While we face COVID-19 together we acknowledge that many of us have understandable stress and worries. Managing stress levels and mental health is a task that many of us will need to tend to. Below are a few general guidelines and suggestions.

Un fortunately, stress is normal. We evolved stress and anxiety to help us stay alert, energised and focused. Some extra anxiety and worry is unavoidable during a time like this.

Know your own signs of elevated stress and anxiety (e.g., irritability, tension, excessive worries). Persistent high stress can become exhaustion and burnout. Monitor your own wellbeing.

Focus on actions that you can control and that will help calm your body and mind. We cannot be relaxed and stressed at the same time.

Look after your body. Exercise is an excellent way to discharge the nervous energy of “fight/flight”. Get enough sleep, eat well and avoid excessive alcohol and drugs.

Drop into your body. Use your body and five senses to lower arousal. Pause. Come back into your body (e.g., pushing pressure with your feet into the floor, straighten your spine, stretch, drop your shoulders). Notice bodily sensations. Take a breath through your nose. Hold. Exhale. Hold. Repeat.

Notice and name your thoughts and feelings rather than pushing them away. Label them with language (e.g., “I am feeling scared, on edge, lonely”). This helps activate soothing pathways in your brain and helps a feeling pass.

Notice what is going well. Remind yourself of 5 things/people/qualities that you are grateful for. Gratitude helps balance what your brain pays attention to and is associated with improved mood, sleep and relationships.

Use what has helped in the past. You will have got through tough times before. Remember your own character strengths and past ways of coping.

Pause and get in contact with the present. Notice what you can see, smell, hear, feel (e.g., warmth, cool, touch). Listen to the sounds of nature. The brain’s soothing pathways helps settle the “fight/flight” part. It can be done formally (e.g., Smiling Mind app) or in moments. Do not expect “results” or to “clear the mind”. If your mind wanders, keep returning to the present moment (your breath, your senses). Be gentle with how you talk to yourself. The aim is just to keep returning to what is happening right now.

Stay connected with others. Reach out to whatever social channel offers you the best support. Share your worries with others.
Exercising at home

Now that gyms, pilates, team sports, swimming pools, leisure centers etc. have closed – it’s time to get creative exercising at home.

Working with equipment
- Jogging on a mini trampoline
- Treadmill walking/jogging/interval training: rent a treadmill
- Exercise bike – read, listen to music, watch TV
- Turn your road bike into an indoor bike
- Skipping – get a rope the right length for your height – Bunnings
- Hand weights, bar bells or cans of tinned food for handy weights

No equipment? No worries!
- Walking outside in the fresh air & sunshine
- Dog walking to keep your furry friend happy and healthy too
- Strengthening exercises: squats, mini-squats, heel raises
- Step training – find a step – turn on music and alternate 20 steps left and right legs leading – build up number / time / fitness
- Stair climbing – house with multiple levels / park / garden with steps – increase the number as you get fitter and stronger
- Sit to stand exercise – sit in a standard height chair – stand up & sit down multiple times: great for strong toned leg & butt muscles

Try these online..
- An online service for people with CF [www.beamfeelgood.com](http://www.beamfeelgood.com) including Yoga classes – U Tube also offers array of yoga classes
- Virtual online cycling with others: [zwift.com](https://www.zwift.com) – 6 worlds with 80+ routes – you can ride in the scenic Alps with international riders
- Pilates online, anytime: [pilatesanytime.com](http://www.pilatesanytime.com)
- Ballet at home: U Tube - use the back of a chair for a barre
- Dance classes: U Tube has many options – turn on your music

Fun with the kids

Exercise in the park with your children – they cycle while you walk / interval run – ball games. Teddy bear hunting to clock up daily steps Make a photographic collection of encouraging messages chalked on pavements - post your own and share with friends & family

Individualised exercise program

‘Exercise is the elixir of life’ – for a unique program in your personal environment please email Brenda Button at: [b.button@alfred.org.au](mailto:b.button@alfred.org.au)
Contacting us

What’s changed?
The CF nursing roles will be changing as the situation evolves and this will include our access to different phone numbers. We would like to request that all of our patients please avoid SMS/texting the outpatient nurses mobile. The CF nurse coordinators will be sharing multiple phones to remain accessible to you, so our usual phone number may often be diverted.

Monday – Friday: 830am – 5pm
As always, if you are unwell or have any concerns regarding your Cystic Fibrosis or overall health, including questions about COVID-19 testing, please phone the Cystic Fibrosis nurse coordinators, Felicity, Elyssa, Olivia and Carmel on 0418 596 938.

If you are in need of an appointment, scripts or a medical letter, please email us at Cysticfibrosis@alfred.org.au. For any and all other general enquiries or requests, please email us and we will get back to you as soon as possible. This email address is manned during business hours only.

Saturday’s & Sundays: Between 10am and 2pm
We will now have a CF nursing coordinator ‘on call’ over the weekends to talk to you if you have become unwell. The on call CF nurse is available to you if you are experiencing viral symptoms; including fevers, increased coughing, breathlessness, or if you have been exposed to someone who has or may have coronavirus. For all other non-urgent matters, please call or email us during business hours.

Out of hours
If you are unwell with a fever, cough or breathlessness, contact The Alfred on 03 9076 2000 and ask to speak to the respiratory doctor on call, who will provide advice depending on the severity of your illness.

Our psychosocial team
As always, our whole team is here to support you with your CF care, your emotional health and other concerns (e.g., financial stress). Most services are now offered remotely (phone or tele-video chat). Please send us an email if you would like to speak with our psychologist, Anthony Talbot, or our social worker, Nick Alaimo. During business hours, Nick can also be contacted via the social work department on 9076 3026.

Medication reminder
We encourage you to keep track of your medication supplies and repeat prescriptions. Please inform us 2 weeks before your medication supply is due to run out. To help us streamline your request, please check all of your medications and provide us with a list in a single email.
Our plan

Admissions
The process for planning an admission remains the same as usual – if you become unwell and you need advice, please call the CF Nurses (Felicity, Olivia, Elyssa and Carmel) on 0418 596 938. At this stage, all planned admissions (eg. Scopes, Iron infusions etc) are going ahead as planned. We will notify you if this changes.

Outpatient clinics
Appointments will now be offered via telemedicine, to reduce the need for you to come into the hospital. Face to face appointments in our clinic rooms will be arranged on an as needed basis. You will still see your usual CF team in your telemedicine review, i.e.; the doctor, physio, dietician, and psychologist and/ or social worker. We may ask you to do any required blood tests at your local pathology center. For appointments, please email cysticfibrosis@alfred.org.au

Medications & scripts (including Alfred-only medications)
We suggest that you check your scripts and please discuss these and your ongoing supply needs (medications, supplements, physio equipment etc.) during your telemedicine appointment.

We are working together with the hospital pharmacy to arrange for you to have an increased supply of Alfred Only medications. We will keep you updated as this plan is finalized. Where possible, please visit your local pharmacy to obtain medications.

Work/ Travel / Study
We encourage you to think of alternative arrangements that help you to avoid exposure to large crowds. Practice social distancing and where possible, consider working or studying from home.
We can assist with generic letters around supporting your requests regarding leave, but please bear with us while we work out way through this busy time.

Who should I contact if I have symptoms?
If you are unwell with fever, cough or breathlessness AND have come into contact with anyone who has been diagnosed with COVID-19, please do not attend your outpatient appointment. During business hours, please contact us to discuss your symptoms and treatment plan. After hours, contact The Alfred on 03 9076 2000, who will provide advice depending on the severity of your illness.