

WCH: Paediatric Cystic Fibrosis patients

How to keep yourself well while isolating at home

We understand that this is a very worrying time for families with a child or young person with Cystic Fibrosis and want to reassure you that your CF team are still available when you need us. All of the social-distancing measures that have been put in place by the Australian Government significantly change the way that we live our lives and we recognise the impact that this will be having on our Cystic Fibrosis community.

It is particularly important at this time that children and young people with Cystic Fibrosis keep as well as possible. This means maintaining all of your regular medications and being extra vigilant with your airway clearance sessions. We have put together some information from our multi-disciplinary team to help guide and support you while you are isolating at home

School

We have been following the updates of SA Health on a daily basis and as many of you have seen, the number of new cases in SA has been very low or zero recently. This indicates that the community transmission rates are very low to negligible.

The WCH CF team at this stage **DO recommend children with Cystic Fibrosis return to school**, however we encourage you to speak to your specialist if you have any concerns.

We understand and also support families who wish to keep their children at home and strongly encourage these families to speak to their schools to ensure that there are adequate online education opportunities.

WCH Hospital School

The WCH hospital school can provide some online learning support through the video conference software Web Ex, particularly if your normal school cannot provide this. If you would like to learn more, please call the Hospital School on 8161 7262.

Activities and education resources

There are lots of great activities and ideas out there to keep your children learning while outside normal school, including a learning program run by the ABC - visit education.abc.net.au for more information.

Another great activity to keep younger children busy and active is the 'Adelaide Bear Hunt'. There is a [Facebook group](#) that you can follow which encourages everyone to put teddy bears or soft toys in their windows or yards to allow children and families to go on a 'bear hunt' around their neighbourhood.

Look out for teddy bears and count how many you can find on your next walk!

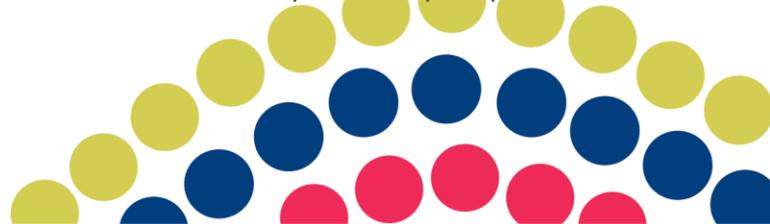
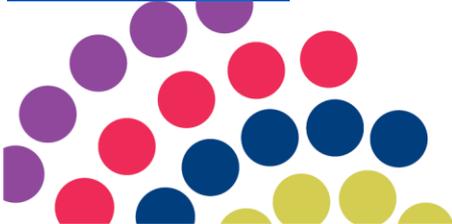
Cystic Fibrosis clinic

At this stage, there are mixed methods of appointments for children and adolescents with Cystic Fibrosis. This is organised by each consultant for their own specific patients based on complexity of their health needs.

Some children are offered telephone calls or videoconference consults and some may still need to attend the hospital clinic for surveillance measures (such as sputum collection and lung function measurements).

Logistics to support home-based clinic reviews are being finalised and appropriate equipment has been sourced to support this, such as portable spirometers and suction units, although the timing of the arrival of equipment may be a few months away.

We will be in contact with families in due time to update on this. We recommend that families contact the CF clinic team on 8161 7234 should they have any enquiries.



What to do if your child develops new respiratory symptoms

We are recommending that families follow the usual process when they develop new respiratory symptoms.

Contact the CF nurse via switch board on 8161 7000 and pager 4398 to discuss management during business hours, or contact the on-call Respiratory Consultant after-hours. If you are really concerned, present to an Emergency Department.

If your child has a fever, a dry cough, sore throat, fatigue or shortness of breath and you are worried that they may have COVID-19, you can call the WCH COVID-19 hotline for advice on 8161 7306, or you can call the CF nurse to discuss the symptoms and your concerns.

Respiratory Hospital in the Home service (RITH)

The Respiratory Hospital in the Home service is still functioning as normal. If your child requires an admission you can access the RITH/HITH service as usual (depending on where you live and admission criteria).

Extended Hospital in the Home service (eHITH)

The extended Hospital in the Home (eHITH) physiotherapy service is also available. If your child has developed a wet cough and would benefit from some physio support in the home, we can refer you to the eHITH program, call the CF or HITH nurse to discuss:

Amy (CF Nurse Consultant) - pager 4398
Jess (HITH Nurse Consultant) - pager 5562

Both RITH and eHITH are subject to location and availability of the service. You can discuss this further with the CF team.



For more information

Respiratory and Sleep Medicine
Division of Paediatric Medicine
Women's and Children's Hospital
72 King William Rd, North Adelaide SA 5006
Telephone (08) 8161 7234



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Flu Vaccine

The flu vaccine is now available when you attend the CF clinic for an appointment, as in previous years. If you are not attending a face to face appointment, there are a few options to get the vaccine:

- Make an appointment at the WCH Immunisation clinic by calling 8161 6316
- Make an appointment with your GP. Many GP clinics are offering a service where you don't attend a waiting room so that you have no contact with other patients.
- Some local councils are running a community flu vaccine program into which you can book.
- For people over 10 years- you can access the Government funded program through most community pharmacies

Airway clearance

It is really important to maintain your normal physio airway clearance practices at this time.

We want people with CF to have the best lung health possible heading into winter and in preparation if you are exposed to viruses.

As you know, lungs that are full of mucus are a perfect environment for bacteria and viruses to thrive, so keep up the good work and keep healthy.



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How to stay active during self-isolation

At the moment, SA Health approves of exercise outside with your family group.

Walks and jogging

Take a walk around the block or to your local park keeping at least 1.5 metres away from other people. You are requested to avoid using playground equipment.

[Walking SA](#) have an awesome list of walks around the state, so check out the website for a walk near you; the current recommendation is for "local" travel or a 10 minute drive away from your house.

Maybe your family could try some jog/walk exercise: jog for 20-30 seconds, walk for long enough to catch your breath and repeat. Start with a total of 5 minutes if you are new to jogging and build up.

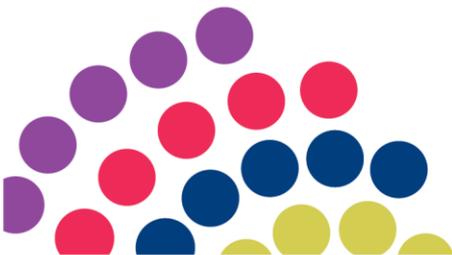
[Couch to 5K](#) is a program that has been designed to get just about anyone from the couch to running 5 kilometers or 30 minutes in just 9 weeks.

Online inspiration

The internet has a large number of exercise videos and ideas. [BEAM](#) currently has a 2 month free subscription and has yoga, strength and aerobic fitness videos designed by a physiotherapist for people living with CF. Use the code '**BEAM-STAY-WELL**' to access the free subscription.

BEAM is more suitable for older children, whilst other sites are designed for younger children. Simply google "exercise videos for children" and you will find many videos to promote physical activity. This will help you find something that appeals to your child.

Now is the time to dust off your bikes, scooters, rip sticks, trampolines, skipping ropes and balls and to spend some time outside getting your body moving and your heart pumping faster.



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Supply of medicines

SA Pharmacy has put together some consumer information about accessing medicine during this time (attached).

As a reminder, supply is currently limited to one month (or a standard PBS supply quantity) for all metropolitan patients and up to three months' supply for all country patients.

The WCH pharmacy recommends that, where possible, PBS medicines are dispensed by your local community pharmacy to avoid the need for you to come into hospital.

For medicines that are only available from the hospital, the WCH pharmacy can supply your medicines and arrange for them to be couriered to a location closer to your home (e.g. your local pharmacy).

This service will be provided free of charge for all patients during the COVID-19 outbreak (until 30 June 2020). If you wish to use this service, please speak with a pharmacy staff member or let us know which pharmacy to deliver it to when placing your email order.

Update from dieticians

During this difficult time, there are various nutrition considerations we need to be mindful of for young people with Cystic Fibrosis.

Rather than re-inventing the wheel, we are posting links to two resources developed by some of our interstate dietitian colleagues that cover nutrition and immunity, food safety, and practical information about accessing food whilst social distancing or self-isolating. These are also both available on the CF Australia website:

[Maintaining Good Nutrition for Individuals with Cystic Fibrosis during COVID-19](#)

[Immunity, Nutrition, Cystic Fibrosis and COVID-19](#)



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The information about Woolworths and Coles in the above link is also relevant in SA. The phone number for foodbank in SA is 8351 1136 and if needed our CF social worker can be contacted regarding information about other supports that may be available.

Monitoring weight and height at home

In terms of monitoring growth and nutrition, we need to obtain accurate height and weight measurements when not attending the hospital for clinic appointments. Please weigh and measure your child prior to any scheduled phone or telehealth appointment to help with our clinical assessment.

Accurate weights are important for helping us ensure your child is meeting their growth goals, which is an important factor to consider as we know well that nutrition status is linked to lung function.

Accurate height measurements are important for two reasons: they allow us to accurately calculate BMI (body mass index – one of the fundamental measures of nutrition status in people with CF) and because height measures affect lung function reference ranges, so an inaccurate height may result in an incorrect interpretation of your child's PFT results.

We would encourage families, if they don't already own some, to purchase some stand on digital bathroom scales. These can be obtained for approximately \$15 from retail stores.

To measure weight, place scales on a hard, flat surface (not carpet) and take shoes and heavy clothing off when weighing your child.

To measure height, shoes should be off and the child should stand tall against a wall, again on a hard surface (not carpet).

Use a flat object on top of the head to form a right angle with the wall and make a mark on the wall, before using a tape measure to measure from the floor to the mark. This [link](#) explains this process in detail and includes a diagram.

Jodi and Natalie (CF dieticians) are available to answer any specific questions or to address any concerns you may have around nutrition, weight or food during this time. They can be contacted via the WCH switchboard.

If you are having a phone or videoconference consult in place of your usual clinic visit, we can link in with you after speaking to the doctor if required, as would be the usual practice in clinic.

Mental Health

The outbreak of COVID-19 has not only changed the way we have all been going about our lives, but also created many new challenges. We recognise the impact that the current situation could be having on children with CF and their family's mental health.

The WCH CF Psychologist has put together some information and suggestions for families on managing at this time, which will be sent as a separate publication soon.



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