



Starting School

A guide for parents and caregivers
of children with cystic fibrosis



About this guide

This guide is for New Zealand parents who have a child with cystic fibrosis (CF) starting primary school. It has been developed together with *'Starting school: A guide to cystic fibrosis for primary schools and teachers'*.

It offers practical advice about topics to discuss with your child's school and teachers, and offers tips from other parents of school-aged children with CF.

About Cystic Fibrosis New Zealand

Established in 1968 as a volunteer support group for parents with a newly diagnosed child, we dedicate ourselves to shaping a brighter future for everyone with CF.

As people with CF live longer and have a better quality of life, there are many life transitions, milestones and challenges to manage along the way. We offer personalised support, whether it is emotional guidance, practical advice or financial assistance, to individuals and their families throughout their changing journeys.

Our team of fieldworkers visit and support families, provide information packs, cover the costs of essential medical equipment, hospital allowances, welfare assistance and other means of support. We also fund CF research and advocate on behalf of the community for better access to services and care.

As well as our national office, based near Starship Hospital in Auckland, we have regional branches that are run by CF families for CF families. The branches provide invaluable friendship, advice and a caring support network.



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Starting school

Starting school is a big milestone in every child's life, and as a parent of a child with CF, it usually comes with a few extra challenges and worries.

Good communication with your school and teachers is key to a smooth transition into school life and to ensure your child's needs are understood by everyone involved.



We recommend organising a meeting with the school and providing them with **'Starting school: A guide to cystic fibrosis for primary schools and teachers'** before your child starts, so there is time to answer any questions the school has or to discuss any individual needs not included in the guide.

Talk with your CF nurse or CFNZ fieldworker if you need any additional information or help with transitioning to school.

Topics to discuss with your child's school and teachers

Infection risks

Minimising infection risks – from other students and the environment, is often a parent's biggest worry when their child starts school. If you're concerned about infection risks at school, and the potential impact on your child, you are not alone!



- *Talk with the school and your child's teacher about areas of most concern, such as stagnant water (e.g. fish tanks, vases, pool changing rooms), vegetable gardens and compost.*
- *Ask if there is another child with CF at the school.*
- *Ask to be notified of activities where there may be an infection risk, such as impromptu gardening or nature walks. Your child doesn't necessarily need to sit these out, but teachers may need specific guidance from you so they don't over or under-estimate the risks.*
- *Your child should use their own stationery if pens and pencils are shared – this way you'll know it's only your child biting on the end of their pencil and not everyone else.*
- *Encourage regular cleaning of chairs, tables, sinks and shared equipment such as iPads.*
- *Ask about the school's policy regarding sick children attending school and if it is strongly enforced.*
- *Ask to be notified if there is an outbreak of diarrhoea, gastroenteritis, chickenpox or other infectious diseases. In most cases you don't need to know who it is, just which classroom is affected, so you can make an informed decision about the risks to your child.*
- *If you and your child feel comfortable to tell classmates about CF, consider sending a letter or email to parents explaining the impact CF has on your child.*
- *Sick children visit the sick bay – which is not the best place for your child! Discuss with your school on identifying another place your child goes to when they're unwell.*
- *Encourage the use of alcohol gel in the classroom and to use liquid soap and paper towels for washing and drying hands – no shared towels or bar soap.*
- *Make sure your child's classroom is well ventilated, dry and free from mould or damp.*



"When my daughter started school, we agreed I would supply wipes and Dettol spray for her classroom and keep these topped up. Her teachers are good at letting me know when I need to bring in some more and it's my way of positively helping the school and feeling like I have some control over the cleanliness of her classroom."

"I'm quite lucky with my school because they take germ control really seriously. I think part of that was being able to visit the school and explain things to them. My daughter has her own sink in her classroom, and they clean it down after every use. They are really committed to keeping her healthy."

"When my daughter started school, one of the ways I could help to minimise her risk of catching coughs and colds was to make sure she had her own supply of stationery such as pens and pencils. I know many schools like to share all the school supplies, especially in the early years, but for us it was better if she didn't. It meant only she was chewing on the end of her pencil!"

Pancreatic enzymes

Many children with CF starting school need help taking their pancreatic enzymes.

Adult supervision, either a teacher or teacher aide is important until you all agree your child can manage taking enzymes independently.



• Discuss the best way for your child and teacher to know how many pancreatic enzymes are needed with each food. Try a notebook or a note in your child's lunchbox or wrap the enzymes in cling film with each piece of food.

- It is important your child learns to take pancreatic enzymes independently. Ideally the capsules will stay with your child, either in their lunchbox or school bag, and not in the school office.
- Provide a list of common 'shared food' that your child can have, such as chips, pikelets, muffins and sausage rolls so your child can easily join in with shared morning tea, lunches or birthday celebrations.
- If your child can't swallow the capsules whole yet, show the teacher or teacher aide how to open the capsules and sprinkle onto apple puree or yoghurt.



"The teacher aide keeps a record of the number of enzymes taken and I leave a note in my daughter's lunch box with an explanation of how many are needed that day."

"Our son needs enzymes so he pretty much considered swallowing pills his party trick when he started school!"

"We've put our daughter's pancreatic enzymes inside the lunch-wrap of each item of food which needs it since she was at kindergarten. It has been so fantastic that she can start to own some of the simple management for her CF, and it'll help her so much to adjust to managing her own health as she grows up."

"My son is quite picky with what he eats so I find the best way to manage his enzymes is to put a sticky note on each piece of food, so him and the teacher know how much he needs if he only chooses to eat one or two things."

"I made sure from day one my son understood if he dropped an enzyme not to take it. We always send extra enzymes in case of this. In fact, we fill a whole little container, and when he comes home I can see how many he had and we can talk about whether he had enough (or any) and how we can improve on the system together."

Eating and drinking

You've worked really hard to make sure your pre-schooler eats enough calories to grow well. Starting school means handing over some of that responsibility to your child and teachers.



- Talk with the teacher about your child's diet – especially the need for high-fat and high-salt foods. Ensure other teachers or older students on lunch duty also know.
- Talk about the 'upside-down' healthy food triangle. Foods best for a child with CF are not often ideal for other children.
- If your child takes a while to eat, ask if they can start eating their lunch before the bell goes.
- Ask to be notified in advance of a 'healthy-eating' discussion at school so you can reassure your child their diet is perfect for them.
- Request easy access to their drink bottle, ideally on their desk or table, especially during summer or when exercising.
- Use an opaque water bottle for electrolyte or sports drinks if your school has a 'water only' policy so your child isn't singled out by classmates for breaking the rules.
- Explain your child's increased risk of dehydration and salt loss, and what signs to watch for. They may need to take salt supplements if outside on hot days.
- Talk with your CF dietitian for help with school snacks, lunches and enzyme doses.



"As a typical five-year-old, he was generally too busy to eat at school, plus they are often expending so much more energy every day. So, we concentrated on food when he got home, pretty much a full meal after school followed by snacks, dinner and often a second dinner."

"When our daughter was diagnosed we were told the thing which has made the biggest difference to the lifespan of people with CF is good nutrition. Filling lunchboxes with chips, avocado and cream cheese may not seem like a potential life-saver, but it is!"

"My daughter gets let out before lunchtime starts so she has time to wash her hands properly before eating."

"I usually overfill my daughter's lunchbox so she can pick and choose what she feels like eating. If the school has 'lunchbox monitors' it's really helpful if they understand children with CF may not eat everything in their lunchbox every day, and that's okay! It also helps to not assume their high-fat and high-salt foods are unhealthy or pass judgement."

"It's helpful if teachers understand why my son is eating foods thought of as unhealthy and he's not made to feel bad about it by other kids. If his class is going to have a session focusing on health and healthy foods I want to be told beforehand, so I can confirm with my son his diet has to be different to what the school says."

Sports and exercise



Your child should participate as much as they can in physical activities and school exercise.



- Ask teachers to encourage your child to join in with school exercise activities. Advise teachers how much they can encourage your child to exercise and when it is okay to sit out and rest.
- Tell the teachers if it's normal for your child to cough during exercise and ask to be notified if their coughing is worse than usual.
- If your child uses an inhaler, make sure the teachers and your child know how and when to use it.

"We always mention to the new teacher at the start of the year about our son's CF and possible issues to watch out for. Participating with other children, in all activities, has been our main goal for our son. Because physical activity is very good for children with CF we never suggested our son shouldn't participate, especially in physical education."

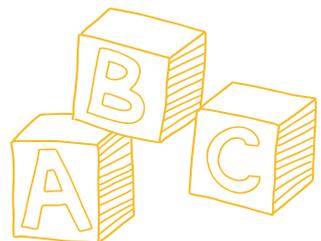
"I think learning to put your hand up and ask to please use the bathroom is actually a skill. Our school has spare uniforms and my son did come home one day in different trousers... there had been an accident. He was very young and it hasn't scarred him for life! I guess the spare uniforms are there for a reason - he probably wasn't the only one that week. It must have been handled well as it never happened again."

Toilet breaks

Quick and easy access to a toilet helps with frequent toilet breaks.



- Ask for your child's classroom to be near a toilet and sink if possible.
- Ensure that your child will be allowed to use the toilet when they need to and without delay.
- Ask to be notified if your child is going to the toilet more than usual.
- Ask for wash basins, floors and counter-tops to be kept clean and dry, to reduce the risk of stagnant water.



School absences



Clinic appointments, hospital admissions and daily CF treatments can impact on school attendance.



- Get a recommendation from the teacher of online learning programmes your child can do at home or in hospital.
- If your hospital has a school or teachers, ask them to liaise with your child's teacher.
- Explain your morning routine and how it can impact on getting to school on time.

"I think it's important for teachers to understand the stress children may be under in the mornings to get physio done. It's likely when they get to school they have already been 'working' for probably 40 minutes at something they must do perfectly and can't avoid. Things get left behind and forgotten in the rush sometimes; there is just no time to relax and sometimes no time to think!"

"The morning school routine is awful - we still struggle. We're always five or ten minutes late. I was really lucky I was able to speak to all the staff and explain about cystic fibrosis. All the staff were really engaged and asked lots of questions. I explained what our morning routine is like, I get up at 6.30am to get everything going but it is a struggle. We try really hard, and thankfully the school understands. I am hoping things will get easier as she gets older though."

"We've always reminded each new teacher that our son has already been up and being made to do things a lot earlier than most children."

Other students

It is up to you and your child about who you tell, and how much information you share, about CF and how it impacts your child.



- It's helpful if your child has some simple answers to common questions classmates may ask.

Examples:

- Q** Why are you taking that medicine? (pancreatic enzymes)
- A** "It's so my tummy doesn't get sore."
- Q** Why are you always coughing?
- A** "My lungs get a bit sticky, so I need to cough."

"It's important your child knows other kids have conditions where they might have to do treatments, like diabetes, asthma or allergies. So normalising differences, if that makes sense."



"My son sees heaps of other kids around his school with diabetes and allergies and doesn't think his CF is really any different to this. Every year since he started school, the teachers have explained CF, keeping coughs and illnesses away as much as possible, his tablets and his drinks (Fortini) at the beginning of the school year to the class. No kid has ever really mentioned it to him. If anything, they remind him to take his pancreatic enzymes! He is aged eight now."

"Kids are naturally curious and have asked my daughter why she takes pills with her food. She just tells them they stop my tummy from getting sore and that's usually the end of it really. I think children of a young age can be quite accepting once their questions have been answered."

"We operate on a need-to-know basis in terms of who we tell about our son's CF. If anyone asks I would never lie or give my son the impression it's something to be ashamed of, but we decided where possible we would leave it up to him to make the decision how he wants to handle this as he gets older. To us, this is also part of not letting CF define him as a person."

If more than one child with CF attends your child's school, a strict management plan must be developed due to the risk of cross infection.

Your CF fieldworker or CF nurse will work with you and your school to develop a plan according to the Guidelines for Infection Prevention and Control for People with CF in Non-healthcare settings: CFNZ position statement intended for people with CF and their family/whanau. The position statement is available on the CFNZ website or from your fieldworker.

School trips

Going on school trips is part of normal school life, and there is no reason your child shouldn't join in.

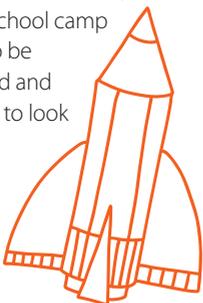
Talk with your child and their teacher about what they may need on the trip, such as pancreatic enzymes, enough water, antibacterial hand gel, paper towels and tissues.

Find out where the trip will be and discuss any potential infection risks and offer advice about managing them.

A lot of school aged children with CF are pretty good themselves at knowing the best way to look after themselves, so make sure they're involved in the planning as well.

Most school trips need parents to come along and help and it's a personal choice whether you go along or not. If you're not going to be on the trip you can always ask for a contact number in case you have any concerns, and make sure another parent or teacher has your contact number, so they can call you if they have any questions.

When your child is older, going on school camp should also be encouraged and something to look forward to.



"I remember the first school trip my five-year-old went on was to the pet store. Very cute - possibly not a great idea for a child with CF. Every mother wanted to go on the trip, and so I wasn't chosen to attend. I mentioned to the teacher I was a bit concerned, and she said, just come to the pet store at the same time as the class. So I missed the bus trip but was with the class at the pet store... with a lot of other anxious first-time class trip parents! Funny."

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"We are in a big school, in an Auckland suburb, but still managed to get to know enough other parents in the class so there was always someone (as well as the teacher) who knew about CF. I've found on school trips the teacher is often overwhelmed with the stress of the event, let alone some extra worry like a child with CF! Having that link to another parent that could have my child in their group was definitely helpful."

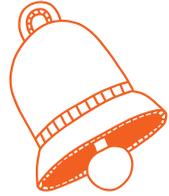
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"For the kids who love hiking, adventures and off-grid activities - it's totally possible with CF! My son went to Great Barrier Island for a week with his school and did every possible scary and adventurous thing. He went kayaking, slept on the beach, waded through streams, abseiled and went sea cave swimming - I was glad I wasn't there otherwise I think I would have had a heart attack! It was a fantastic learning curve how to handle his meds even off grid. There was no sterilisation available and no sterile water for nasal washouts, so we made a plan with our CF nurse. He took two portable nebulisers, enough nebuliser parts for each day and loads of meds on the ferry across. He did so well and probably stuck to about 75% of his treatments and pills. The best part is, he had the time of his life."

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Emergency situations

If your child has a PICC line, PORT, feeding tube or other medical device, give the school and teacher information about how to manage them at school and what to do in an emergency. Your CF nurse can provide you with information specific to your child's needs.



*He is
happy
and that
is all that
matters."*

And lastly...

"My son is completely oblivious. He's like, what? School is school. No memories of his first day, or first teacher or having to take pills in his lunchbox for the first time. It's all so normal for him - he's now 13.

I guess this is how we wanted it to be after all... this is what we were striving for. He turns up, listens (hopefully), learns, participates, misses a bit for appointments, has the odd day off and the odd admission (but we've never missed much school as I've always done home IVs).

This is our normal, and our son now thinks it is his normal too. And his friends and schoolmates now think it is normal as well.

He started college this year, and all that work at primary school - the yearly meetings with teachers, the notes, the enzymes and antibiotics at school - it was all practice for now, for his life, to help him grow up and be independent.

At college he has already been on camp, been sick and had to catch up on school work, signed up for surfing. He texts me after school to say he is going to a friend's house and has made a new peer group.





A heartfelt thank you to the families who gave us valuable insight into their personal experiences with cystic fibrosis, through both words and photography. We could not have completed this project without your help.



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Lastly, thank you to the fieldworkers, clinicians and medical experts who shared their knowledge and expertise on cystic fibrosis, and took the time to review and fact check this guide.

This publication has been written as a general guide for parents and caregivers of a child with cystic fibrosis starting primary school in New Zealand.

While Cystic Fibrosis New Zealand (CFNZ) has consulted with healthcare professionals and families of children with cystic fibrosis to ensure the information is accurate, it does not substitute specialist advice from your medical team.

CFNZ will not be held liable for inaccuracies or omissions.