CYSTIC FIBROSIS NZ

Starting School
A guide to cystic fibrosis
for primary schools and teachers

cfnz.org.nz

About this guide

This guide is for New Zealand primary schools and teachers who have a child with cystic fibrosis (CF) starting at their school. It aims to give you a better understanding of what CF is, how it impacts on the child and their family and what teachers can do to help the child succeed at school.

It has been developed together with *'Starting school: A guide for parents and caregivers of children with cystic fibrosis'.*

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, cover the cost of essential medical equipment, provide information packs, 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. They provide invaluable friendship, advice and a support network.

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If you would like to know more, please get in touch.

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TOP TEN THINGS TEACHERS NEED TO KNOW ABOUT CYSTIC FIBROSIS

Cystic fibrosis (CF) is a genetic condition.

It mainly affects the child's lungs and digestive system, causing problems with breathing and how their body digests food.

Children with CF may not look sick, but it takes a lot of work to stay well.

Most children with CF have twice-daily chest physio, take daily medications, have pancreatic enzyme capsules with their food and sometimes need high energy supplement drinks. Daily treatments can take between 1–2 hours a day – a lot to fit into a school day for young children. All these treatments mean they usually get up earlier than most of their classmates and can become tired in the afternoon.

Children with CF can get very sick from certain bacteria and viruses that are harmless to other people.

At school, stagnant water such as in fish tanks, flower vases, swimming pool changing rooms and puddles can grow bacteria that can cause serious lung infections for children with CF. Compost bins, worm farms, wet bark and drains are also places where children with CF are more at risk.

Simple viral infections such as the flu or a cold can mean children with CF need more intensive treatments such as antibiotics and more chest physiotherapy.

Please tell parents if your school has an outbreak of an infectious disease such as chickenpox, whooping cough, diarrhoea or vomiting. Parents are the best people to decide what the risks are for their child and how to manage them.

CF does not affect a child's intelligence.

You should expect the same academic ability and behaviour as you do from the other children in your class.

Children with CF need to eat a high-calorie, high-salt diet and stay well hydrated.

Their body finds it harder to digest fat and nutrients from food so they need to eat more high-fat, high-calorie foods as part of a balanced diet. They also lose more salt in their sweat, so they can become dehydrated easily, especially in hot weather or during exercise. They need to drink plenty of water and eat more salty foods than other children.

Children with CF may have a chronic cough.

This doesn't mean they have a cold or are unwell, but CF causes mucus in their lungs to become thick and sticky and coughing is the best way to get rid of the mucus. Their cough is not contagious to other people.

Handwashing is important for everyone.

Encourage everyone in your class to clean their hands regularly by using hand sanitiser or washing with soap and water, especially after coughing, before eating and after going to the toilet. When using soap and water use paper towels to dry hands and ideally liquid soap should be available.

Children with CF may need to go to the toilet frequently.

They may need to go urgently and often their poos can be quite smelly. Quick and easy access to a toilet, and a sink to wash their hands, is important.

Exercise is important.

Regular exercise helps to keep lungs and bodies healthy and should be a part of every child's school day. Children with CF should take part in physical activity just like their classmates.

Good communication with parents is key.

Regular communication between teachers, parents and children is key to making sure children with CF reach their full potential at school. If you have any questions about CF the best thing you can do is ask.

Understanding cystic fibrosis

Cystic fibrosis (CF) is a genetically inherited condition some children are born with that mainly affects their lungs and digestive system. It is caused by a faulty gene that has been passed down from both their mum and dad and is usually diagnosed soon after birth.

When we don't have CF, our bodies make mucus that is thin and slippery and works as a lubricant to help protect us from infections and to keep the insides of our bodies working well.

If we have CF, our mucus becomes thick and sticky and blocks the tiny tubes of many of our organs.

In the lungs, the sticky secretions are difficult to cough up and viruses, bacteria and fungi can become trapped under the mucus. This can cause inflammation and infection and make it harder to breathe.

In the digestive system, thick secretions also block the flow of digestive enzymes from their pancreas to their duodenum (top part of the intestine) where they are needed to help break down food. Without these enzymes, fats and nutrients can't be absorbed so it is much harder for children with CF to put on weight.

Get to know the symptoms

Most of the common symptoms of CF are due to thick secretions in the lungs and pancreas.

Some children with CF have an ongoing cough, not because of a cold or virus, but because it is their body's way of helping to clear the thick mucus from their lungs. It is not contagious and it is such an important way of helping to keep their lungs clear, so at school if they have a bit of a 'coughing fit' it is helpful to have tissues on hand or let them leave the classroom if they need to.

It can be embarrassing to always be coughing, especially if they are coughing up mucus, so don't let others draw too much attention to it.

At times, children with CF can get short of breath, especially during PE or other physical activities. They may need to use an inhaler before starting, or during the activity. Talk with parents and the child about what is normal for them, so you know when to be worried and when not to be. If they are coughing more than usual during or after exercise, let the parents know as it may be a sign they are developing a chest infection.

Sport and exercise are strongly encouraged for children with CF, for healthy lungs and overall good health.

Because of digestion problems, going to the toilet is often an urgent event, one that can't be delayed or ignored. Their poos can be quite smelly and they usually need to go to the toilet more than other children. Being in a classroom with easy access to a toilet is helpful, and not having to ask the teacher before they leave the classroom is a big help too.

"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."

Treating cystic fibrosis

There is no cure for CF, so there are treatments children must do each day to stay well. Chest physiotherapy and taking pancreatic enzymes are two important aspects of their treatment.

Chest physiotherapy

Every day, usually twice a day, children have chest physio to help keep their lungs clear of mucus. This can take between 20–40 minutes each time but it can be longer if they are unwell. Chest physio is usually done before school and before bed.

When they are younger, physio is usually done by parents and is a session of percussion (hard tapping) or cupping on their chest. By age 6 or 7, many children learn to do physio themselves with a positive expiratory pressure (PEP) device. Parents still need to watch their child to make sure they're doing it correctly.

A salty solution, called hypertonic saline, is often inhaled via a nebuliser before or during chest physio to help thin the mucus, which makes it easier to cough up.

It takes a lot of work to get children to school on time when you've got more to fit into the morning routine than getting dressed and making school lunches. Physio is an important part of staying well and it shouldn't be skipped in the morning, so some days children (and siblings) might arrive at school a little late.

"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!"

"My daughter gets up quite early to get through all her morning treatments. This means she can be quite tired in the afternoon. Sometimes the teachers forget about how much work it takes for her to stay well."

"Doing physiotherapy and medications usually takes us 40 minutes each morning – and that is when things are going well! If our child is sick or distracted, physio takes much longer and we sometimes end up running late."

Pancreatic enzymes

Most children with CF need to take pancreatic enzyme capsules with most of their food to help absorb nutrients, especially fats.
The number of enzyme capsules they need to take each day depends on what food is in their lunchbox – most parents and children become experts at knowing how many enzymes are needed.

Teachers, parents and the child should develop a plan together to manage enzyme capsules at school. Children with CF who need pancreatic enzymes will always need to take them, so they should be encouraged, right from the beginning of school, to take them independently – this means keeping them in their lunchbox rather than somewhere they have to go and ask for them. Keeping enzyme capsules in their lunchbox also means if they are embarrassed to take it they can do it discreetly.

Children may want to keep spare enzyme capsules at school, either in the classroom or with other medications, so if there is a shared lunch they can easily join in.
It also helps to keep some at school in case enzymes are left at home. The expiry date on enzymes kept at school should be checked regularly and they need to be kept away from sunlight and heat.

If children with CF don't take pancreatic enzymes when they eat they may get stomach pains, wind or diarrhoea. Missing a couple of doses doesn't have any short-term consequences, but over time with more and more missed doses they may struggle to put on weight or start to lose weight.

By school age, some children can swallow the capsules easily, but if they can't, the capsules need to be opened and the granules within the capsule sprinkled onto either apple puree or yoghurt most times they eat. Parents and the child will show you how to open the capsules if they need help. It is important the child doesn't take the granules in water or put them straight into their mouth.

Note: If another student takes the pancreatic capsules accidentally it is unlikely to cause them harm, they may just have diarrhoea or a tummy ache for a while.

"The teacher aide at school keeps a record of how many enzymes my daughter has taken, and I leave a note in her lunchbox saying how many are needed for the day. This works well for us, but I know not every school has teacher aides to help supervise."

"We've put our daughter's pancreatic enzymes inside the lunch-wrap of each item of food that she needs it for 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."

Infection risks at school

Certain bugs can cause long-term damage to a child's lungs when they have CF, potentially impacting on their quality of life, lifespan or opportunities for future treatments. Often parents find the risk of infection from other students and the environment a huge worry, so it is important to listen to parents and understand what the risks are.

Viruses – such as coughs and colds

Children with CF are more at risk of developing serious complications from viral infections. Bugs can get stuck in the mucus in their lungs, causing them to get very sick very quickly. This can lead to longer treatments, extra medications and time off school.

In a classroom of children, especially during winter, it can be hard to keep all the bugs away, especially with younger children. But you can help children with CF to stay well by encouraging classmates to stay at home when they are sick, or minimise the contact children with CF have with other children who have coughs and colds.

Teaching every child in your class to wash and dry their hands well and use hand sanitiser is an easy and effective way to help stop the spread of bugs. Learning how to cough into their elbow and covering their mouth when sneezing are also helpful.

Sharing pens and pencils can be an easy way for bugs to spread – especially when children put them in their mouths. Have one set of stationery just for them. Regular cleaning of chairs, tables and shared equipment such as iPads is also important.

> "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!"

Bacteria, mould and fungus

Some bacteria, moulds and fungi, usually harmless to people without CF, is a risk to children with CF. Bacteria and fungi commonly found in soil, rotting vegetables, composting leaf matter and stagnant water carry the greatest risk. Areas around the school where there is an increased risk include:

- fish tanks
- vegetable gardens
- compost bins
- worm farms
- drinking water fountains
- wet or dry dusty bark
- puddles which never completely empty
- flower vases
- swimming area – especially changing rooms and sides of pools.

Wherever possible, classrooms should also be well ventilated and free from damp and mould.

Childhood illnesses such as chickenpox, gastro, measles and whooping cough can also cause serious and long-lasting consequences for a child with CF. When illnesses are going around your school, please chat with parents and let them know so they can decide how to best manage the risk for their child.

"I'm quite lucky with my school because they took 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."

Many parents with CF work hard to achieve a balance between minimising the risk of infections and allowing their child to have a normal childhood. There is no one-size-fits-all approach to infection control and situations and events will pop up where you may not be sure if it is a potential infection risk. If you're ever in doubt, talk with the child and their parents for guidance.

Note: If possible, have a separate area away from the school sick bay they can go to if they're feeling unwell, to help avoid the spread of bugs.

"Our daughter's school has been great at minimising infection risks in the environment for her. Everybody wants her to stay healthy, and if that means no fish tanks then they're accepting of that."

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

Other children with cystic fibrosis

Because everyone with CF carries different bugs in their lungs there is a risk they can pass these on to other people with CF.

If more than one child with CF attends your school, a strict management plan must be developed due to the risk of cross infection and to ensure the health and safety of children with CF.

A CF fieldworker or CF nurse will work with your school and family 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.

Cross infection, i.e. one child with CF picking up bugs from another child with CF, may also happen if they share equipment, such as iPads, books and pencils.

The risk of cross infection may be higher in enclosed spaces, particularly when there is poor ventilation and children are close together. For example, two children with CF in a classroom is likely to carry a higher risk than two children with CF in an outdoor playground.

Specific times cross infection may occur at school include:

- bus rides
- before and after school care
- lunchtime library times
- music rooms
- school clubs
- assemblies
- school trips and camps
- sports days.

"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."

"Our school is nut-free because another child has a nut allergy. I spoke with the school about my daughter's need for high energy food and that cashews and peanut butter are some of the few things she will eat. The school got funding for a teacher aide who sits with her during lunchtime to ensure she eats her lunch, gets the nutrition she needs, and things are still kept safe for the other students."

"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 lunch boxes with chips, avocado and cream cheese may not seem like a potential life-saver, but it is!"

Eating and drinking

Children with CF need to eat more calories than other children and eat foods higher in salt.

Their lunchboxes usually have some foods which are high in fat such as butter, cheese, full fat milk, mayonnaise, yoghurt, peanut butter, chips and chocolate biscuits. This is part of a healthy CF diet and helps children gain and maintain their weight, which is something many children with CF struggle with.

They also lose more salt in their sweat, especially during summer, which puts them at risk of dehydration. They need to eat salty foods such as chips, pretzels and other savoury snacks and sometimes drink sports drinks, electrolyte replacement drinks or take salt tablets. Encourage easy access to their drink bottle, preferably on their desk or table.

Some children may need more time to eat – their appetites may not be great, but it is important they have lots of time at morning tea and lunchtime to eat what is in their lunchboxes.

If your class or the school is having a discussion about healthy eating, please let the parents and child know in advance, so they can talk at home beforehand about how their diet is just perfect for them. Hearing about 'unhealthy food' can be confusing if your lunchbox contains some of these foods you need.

Sport and exercise

Much of the treatment for CF focuses on maintaining healthy lungs. Normal everyday childhood exercise and school sports to get them moving is great for their lungs.

Children with CF should be expected to participate in school physical activities just like other children. However, they can sometimes become tired more quickly and may need to have a rest, but they should always be encouraged to participate as much as they can.

For many children with CF, exercise is a normal part of their day and an area where they excel. All children with CF are encouraged to participate in regular sporting activities for good lung health and overall fitness.

School absences

Living with a chronic illness inevitably means spending some time at hospital, either for routine appointments or an inpatient stay in hospital. Some children spend very little time away from school but others may need to be in hospital frequently.

Children with CF should be expected to keep up with their peers academically and good communication between teachers, parents and the child can really add to their success at school.

Children may have planned admissions to hospital, so organising work for them to do while they are in hospital is always helpful. Some hospitals have teachers you can liaise with to keep their school work up-to-date.

> *"A hospital admission can be really boring, especially if they're not too unwell. Lots of kids will be glad to have some school work for something to do!"*

> *"My school has recommended some online learning programmes we can access at home, which is great if he's not feeling well and is at home, but is well enough to do a bit of school work."*

Emotional wellbeing

As children with CF integrate into school life they may start to become aware of how CF affects them differently than their classmates. Like most children with a chronic illness, there will be times when they become upset or angry about their treatments and the impact CF has on their lives.

Allowing the child opportunities to talk about their feelings and working closely with parents and families can help them work through any issues that arise.

Confidentiality

Some parents and children are very open about having CF, while others don't want other people to know.

There is no right or wrong way for a family to feel about telling other students and families about CF. Talk with the child and their parents before they start school so you know how much information can be shared.

Other children in your class may have questions about why the child with CF coughs a lot or about the 'special' food or capsules they have in their lunchbox. Parents can give you some advice about how to answer these questions, depending on how much they want other people to know.

Most children are great about answering questions and often they are the best people to ask. Even if they don't want to share too much about CF they can usually give good answers to questions classmates have.

All children with CF in New Zealand are cared for by a multidisciplinary healthcare team, including doctors, nurses, physiotherapists, dietitians and fieldworkers. A member of this team can usually be involved in developing a health plan for school in partnership with parents, children, schools and teachers.

TOP 10 WAYS your school can help

1. *Listen to parents and the child – they are the experts.*
2. *Understand the importance of minimising environmental infection risks – these should never be underestimated as exposure to certain viruses and bacteria can make the child with CF really unwell and impact on their lifespan.*
3. *Understand the risk of cross infection if more than one child with CF attends your school.*
4. *Practise good hand washing and drying in the classroom, and school wide.*
5. *Use hand sanitiser in the classroom and liquid soap and paper towels in the bathrooms, rather than bar soap and shared towels.*
6. *Let children with CF have quick and easy access to a toilet and don't delay allowing them to go. Notify parents if their child is going to the toilet more frequently than normal.*
7. *Have a robust school policy about children staying off school if they are sick.*
8. *Sick children visit the sick bay – which is not the best place for a child with CF. Organise another place they can go when they're unwell.*
9. *Understand the different nutritional requirements of children with CF, especially how important high-fat and high-salt food is for a child with CF.*
10. *Let parents know early if their child's behaviour changes. There are many reasons for this – tiredness, dehydration, medications or social and emotional issues.*

CYSTIC FIBROSIS NZ

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