CYSTIC FIBROSIS Western Australia

CYSTIC FIBROSIS WA

Information For New Parents

Government of **Western Australia**
Department of **Child and Adolescent Health Service**

Perth Children's Hospital

Conte

nts

CYSTIC FIBROSIS Western Australia

Congratulations on Your New Baby!

Congratulations on the birth of your new baby. Having a baby diagnosed with cystic fibrosis (CF) can be difficult news to digest and you may have many questions, but know that you are not alone. There are supports available to you and your family which includes your CF hospital care team at Perth Children's Hospital (PCH), the team here at Cystic Fibrosis WA (CFWA) and members of the CF community.

This booklet is a good starting place for parents and other carers (grandparents, aunties/uncles etc) with a baby that has been diagnosed with CF. It will provide you with helpful information as well as some practical tips from other parents and families affected by CF. It is a useful guide as you start your journey with CF.

It is important to note CF affects every child and every family differently. No two children with CF are the same; they are all unique.

Your CF health care team wants to know your concerns. They will always take these concerns seriously, no matter how small you think they are. Always feel free to ask questions and learn more about CF.

As a parent, you will experience all the normal ups and downs of parenting, however, you will also be managing the daily requirements and treatments of having a child with CF. You will most likely feel overwhelmed at first. In time, you will get to know how CF affects your baby and will know if there is something wrong. There may also be times when you feel sad or angry.

"The way I handled and processed the news, and made it make sense for me, it was quite different from how my husband did. And there's no rights or wrongs, everyone does handle it differently and that's actually ok."

"It gets easier; every child is different. You should call on the people who are close to you. Be vulnerable, be sad and don't be shy to ask for help. But also remember, you have this little child of yours and they are still perfect. Take time together doing fun things. You can't be too proud".

This can happen at any time and present itself in different ways. There are people on your CF health care team and at CFWA that can talk to you about your feelings and challenges, to offer you advice, support and referral if required.

It is important to note that with advances in care and treatment, children born with CF today are expected to live full and active lives. They will go to school, get a job, plan their future, and have families of their own if they wish.

CF is just a small part of who they are!

"The progress in CF treatment in the last ten years is phenomenal and it can only get better and better. Have faith there are much better times ahead".

A Letter from Tracey

Our daughter Evie was diagnosed at birth through the Guthrie test. We are a family of two mums, and our daughter Evie was conceived via IVF through a fertility clinic. We didn't know that I was a carrier of the CF gene, or that the donor was too, so it was a big surprise when Evie was diagnosed.

At the time we felt like our world was crumbling when we got that phone call from Perth Children's Hospital (PCH) when she was two weeks old. As a parent, you just want a healthy baby. Then you have this baby with CF and you think, what sort of life is she going to have now? Is she going to have a long life? Will she be in pain? How are we going to take care of her with no family in Australia?

It was such a shock; everything just fell apart in our little 'new mums and family' bliss bubble.

Once she was diagnosed, we went each day to the hospital for a few weeks of education on CF and her care and we just went into auto-mode, because we had to. For myself, I like to know as much as possible. I need all the information, good or bad, and work better with a wider picture, whereas Evie's Mumma, Fiona (my partner and Evie's other mum) works with the now and then. I asked questions about her future. What sorts of drugs will she need to take? what her life will be like? etc, trying to get an understanding of what the future looks like. This helped me to think about her future and more importantly that she was going to be OK. On the other hand, Fiona is very logical; she was asking questions of the doctors about bronchoscopies and what we need to know and do now, not further down the line. Each question we asked we were met with positive, honest and informative responses from our Dr and the CF team at PCH.

The uncertainty at first was difficult as we had never heard of CF, nor did anyone else that we knew. The nurses from PCH were amazing on the day of the phone call and still are to this day. They told us not to Google, which we didn't, and that's advice I'd give to any new parent or family of a child with CF; don't Google! Our family also came over from the UK and South Africa and helped us at diagnosis.

Once we had her meds under control, it felt like we would be alright and as a family our slogan became 'We can do this AND we're doing a good job'.

Another surprise, I ended up with post-natal depression which made everything that little bit harder for us. We tried to keep things pretty standard, treating Evie like any other child, just taking a few more precautions. For instance, when people came over, they were told to sanitise when they walked in the door, and this became a habit that still stands in our house; sanitise then play. Evie is in the habit of sanitising after playgrounds now too, in fact she reminds me to do it even at two years old.

We had to develop some new strategies around managing anxiety because it can all be stressful at times. I started acupuncture to relieve tension in my neck. Fiona started breathing exercises which we started to do before going to hospital appointments or having a bad physio day. Podcasts and stories on or from people with CF were helpful, knowing they are living perfect lives helped us to know Evie would too.

As a couple, we love to go scuba diving. It's our way of managing stress and anxiety. Trying to be an average family just like the rest. Going out and about to coffee shops, wineries, camping, kayaking and doing these things together as a family, rather than treating her like a glass ball. We didn't shy away from anything, and in our opinion, that helped us manage the stress, seeing her do all this with us from a baby to a toddler now, and she's wild!

We still go diving in winter as the visibility is great and we love to catch crayfish when diving. We can't talk under water either which is good to take time for ourselves. We just focus on our breathing and take the beauty of the

ocean all in and come home to Evie a lot more relaxed and grounded with photos of the sea life which she loves to see. We feel that water is a powerful source of calmness, and we love the beach as a family. Some of our friends know Evie's medication well, so they look after her when we go diving.

Doing the things that you love is so important, both together and separately. We take time for ourselves and come home to Evie in a stronger state and in a calmer place. We have really good communication with each other and Evie, and CF has actually brought us closer together. She knows she has it and that she goes to the doctor so he can listen to her lungs and belly. She takes her own doctor set we got her, and it calms her to know the tools they use as she has them in her bag. We practice using them at home before going in and are also honest with her about her 'delicate lungs'. She is braver than us at times getting her bloods and check-ups.

Every hospital appointment is still stressful, even the general appointments. The hospital is great, but every appointment or phone call is just the reminder that she's got this thing called CF.

We do a lot of self-care before going to the hospital. We make sure she is all fed and happy, Fiona and I do our breathing exercises, which Evie sometimes tries with us, and we put some music on and have fun on the way there. We make it a special family day and go to Kings Park for a picnic or somewhere she can do something special afterwards. When she's older she can tell us what she wants to do after the appointments.

We have good friends here, lots of Evie's 'aunties and uncles'. A support network of people that we can phone if needed. Some of them know her medicine and physio, but through no fault of theirs, they don't really understand the emotional and worrying side from a parent's perspective.

We're no experts, but from our experience in the past nearly three years, our advice to all new parents is that it does get easier to manage. Everyone has their own journey, but just the way that every child is different, every CF child is especially different to the other. Call on the people who are close to you. Be vulnerable, be sad and don't be shy to ask for help but also remember, you have this little child of yours and they are beautiful and perfect regardless of CF. Take time together doing fun things. Reach out to CFWA, there is always someone there to talk to and they are amazing help and will connect you to other parents which really helps. They just know what you're going through. It will all be OK.

Congratulations on the birth of your beautiful baby,

Tracey

About Cystic Fibrosis

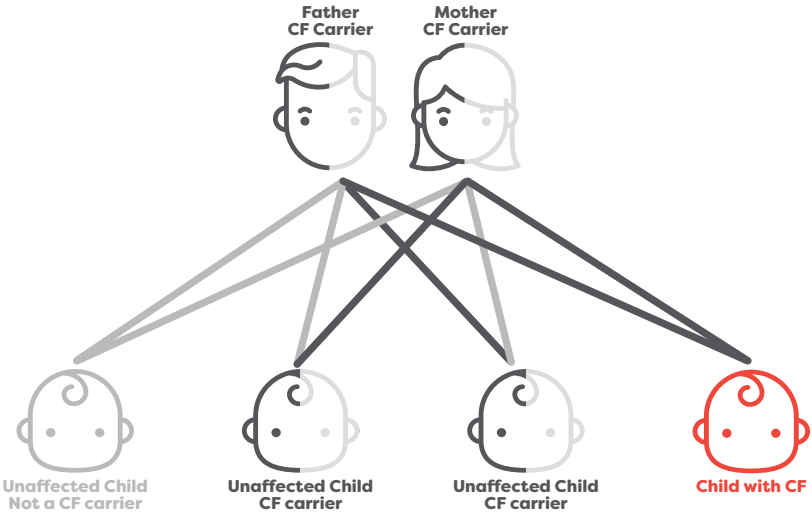
CF is an inherited condition that affects many organs in the body including the lungs, pancreas (in the digestive system) and the sweat glands.

Who is Affected by CF?

CF occurs across the world and affects approximately 400 people in Western Australia (WA). Perth Children's Hospital (PCH) is the primary paediatric care team in WA and looks after approximately 200 children with CF aged from birth to 18 years.

How is CF Inherited?

To have a child with CF, both parents must be a carrier of the CF gene. For many, there is no known family history of CF and their baby's diagnosis often comes as a surprise.



Approximately 1 in 25 Australians carry the CF gene. Carriers do not have any symptoms of the genetic disease and generally are unaware they are a carrier. In Australia, about one million people are carriers of the CF gene.

How is CF Diagnosed?

Most children are diagnosed with CF through the newborn screening test, also known as the Guthrie test. Newborn screening is a simple heel prick test that is routinely performed in Australia when babies are two to three days old.

The test screens for a range of genetic conditions, including CF, and aims to optimise health by early diagnosis and management. The newborn screening test for CF is a two-stage process. If the newborn has two CF genes, a sweat test (as pictured) will then be performed to confirm the diagnosis.

Managing CF in Your Baby

The main areas affected by CF are the respiratory and digestive systems. CF can also affect other parts of the body, such as your child's ears, nose and sinuses, liver, bones and joints. Your CF team will closely monitor for any signs of further complications as your child grows. It is also important to understand that many organs, like the heart and the brain, are not affected by CF at all.

Respiratory System

We all have mucus in our lungs to help filter out bacteria and keep us healthy. In CF, the mucus is thick and sticky and more difficult to clear. It can block the airways, leading to inflammation and infection. Antibiotics are used to prevent and treat infection and daily physiotherapy, or airway clearance, is recommended to keep mucus moving.

> *"Don't be scared of it. It is going to come naturally, eventually, it's just like riding a bike. It takes time."*

Physiotherapy

Daily physiotherapy is usually started as soon as your baby is diagnosed with CF and will continue throughout their life. This helps prevent infection and creates a good routine for you and your baby. Practicing physiotherapy every day ensures you have the skills you need if your baby becomes unwell.

Sometimes, your baby's other health needs may take priority, so don't worry if your baby has not yet started physio.

Your hospital CF physiotherapist will help create an individualised program for your baby and teach you how to do it at home. It may seem overwhelming at first but the more you practice, the easier it will be.

As your child grows, their physiotherapy program will change to suit their needs.

Developing a Routine

It is very important to set up a routine with your baby as early as possible, however, for some babies this may take longer and that is okay. When you and your baby are in a good routine it is easier to keep up with treatments. Here are some physio routine tips:

- Get into a routine as early as possible. There will be good days and hard days as always with newborns. However, with persistence and practice, you will both become more comfortable with treatments.
- Try performing physio at around the same time each day. Children feel more secure if things happen in a similar pattern on most days, even as young babies.
- Aim to do physio before a feed, or at least an hour after to reduce the risk of reflux and discomfort.
- It is worth spending a few minutes doing settling activities (rocking, singing, cuddling) before starting physio so your baby is calm.
- A special physio teddy, blanket or other comfort item can be useful to become a positive part of the routine.
- Try to keep physio positive with lots of cuddles, smiles and laughter. Singing, rhymes and storytelling are also useful.

- Wherever possible, make physio a special time where your child has your undivided attention. This can be very difficult with older siblings around, so try to time physio with their nap or have them set up with an activity they can manage themselves before beginning.
- It is natural to want to stop physio if your baby starts to cry. Try to prevent this by watching and anticipating when they're about to cry, possibly changing baby's position, but not stopping completely. It is important that your baby does not associate crying with physio finishing. Try to end on a positive note.
- Use the beep of a timer or verbal cue such as "1,2,3 done" before you finish physio. This helps your baby begin to understand when physio has been completed. This technique develops a positive, secure environment to help your child gradually accept physio.
- After your physio session, it is helpful to introduce a special activity as a positive association to physio. With a baby, this could be a massage, cuddle, or song.
- Some babies will find physio soothing and may fall asleep. This is fine to continue.
- Incorporate age-appropriate active play into your day, such as tummy time, supported bouncing on a large ball, rolling, tickling and giggling. You could even use a jolly jumper for short periods of time as long as your baby's full foot (not just toes) can push off from the floor.

> *"The most challenging thing in the early years is getting used to a routine, and I think accepting it. The fact that this is our life, and it's not just a 6-month thing, it's not just a 12-month thing, this is life".*

CFWA may be able to help support you set up a routine with your baby at home. For more information, go to: www.cfwa.org.au/what-we-offer/support-programs or contact our physio on **physio@cfwa.org.au**

SCAN ME

For a range of factsheets on physio, go to: www.cfwa.org.au/what-we-offer/resources

SCAN ME

> *"Understanding that in fact she is going to get sick, she is going to get colds, and that's actually not a bad thing. But how we treat it and how we deal with it is what's important".*

Signs Your Child is Unwell

Despite treatment, your child can still get sick, like anyone. It doesn't mean you have done anything wrong. It is important to learn the early warning signs that may indicate that your child has a lung infection.

Changes to Monitor:

Cough - Your baby might start to cough, or their cough may sound different.

Wheezing - Your baby may start making a whistling noise while breathing.

Difficulty breathing - Your baby may be working hard to breathe, breathe faster or be breathless when feeding.

Decreased energy or lethargy - Your baby may start sleeping more or seem less active.

Reduced Appetite - Your baby may have fewer feeds or even refuse feeds throughout the day.

Raised Temperature - Your baby may feel hot and have flushed cheeks.

Some children with CF will not appear to be sick. Changes may still be happening in their lungs, so it is important to continue with treatments and clinic visits even if your child seems well.

If you are concerned about your child, contact the CF team:

During Office Hours:
Contact the CF nurses at Perth Children's Hospital (PCH). The nurses will be able to offer you advice on management. If needed, the nurse will arrange an appointment with the doctor.

After Hours:
Call the hospital, state that your child has CF and ask to speak to the Respiratory Physician On-Call.

Digestive System

In CF, the digestive system also contains thick, sticky mucus and as a result of this, some babies with CF are born with a bowel obstruction, known as meconium ileus. This occurs when the bowel becomes blocked with thick, dark and sticky meconium (babies first poo). In some cases, surgery is needed to clear the blockage.

Around 90% of babies with CF will have issues with their pancreas, which is known as pancreatic insufficiency. People with CF who are pancreatic insufficient will need to take enzyme supplements when they eat or drink to allow their body to break down food and absorb nutrients. Without enzyme supplements, pancreatic insufficient babies struggle to put on weight.

The small percentage of babies whose pancreas functions normally are known as pancreatic sufficient. These babies will not require enzymes but will be routinely assessed during their regular hospital appointments.

Milk

Good nutrition is important in babies with CF and is the first defence against infections that can occur in the lungs. Deciding how to feed your baby may be difficult, given the extra considerations, however your baby's hospital dietitian will support you whether you decide to breastfeed or formula feed, and they should be your first contact for all things relating to your baby's eating and growth.

Breast milk is considered the best option for most babies, with or without CF, as it contains everything needed for growth and development during the first six months of your baby's life. Breast milk contains antibodies which offer some protection against certain infections, such as coughs and colds, ear infections and tummy upsets.

For some women, breastfeeding can be very difficult. Be assured that feeding your baby formula is suitable for babies with CF. It has benefits, too, as you will know the exact amount of milk your baby is having at a feed. Formula also has a higher salt content than breast milk (which is a good thing for babies with CF). In most cases, babies with CF will be able to gain weight adequately on formula milk.

> *"I would pump into a bottle every now and then, to measure how much I'd pumped and then to see how much my baby drank. From this I could estimate approximately how much he would be drinking from my breast on an average feed and estimated enzyme dosage that way".*

Enzymes

Pancreatic insufficient babies will require enzyme supplements with their milk feeds. Your child's dosage of enzymes will change as they grow and as their diet changes. The CF dietitian will help you to manage this, so your child maintains a healthy weight.

When you begin introducing solids, your baby will also need enzymes with most foods. The dietitian will help educate and guide you with determining enzyme dosages.

How Do I Give My Baby Enzymes?

The thought of giving your baby enzymes can feel overwhelming at the start, but it will soon become very normal. Your baby's dietitian will support you throughout the process and provide plenty of education. A quick rundown is:

- Deliver enzymes at the start of every feed. Enzymes are only effective for 30 minutes, so if a feed takes longer than this, extra enzymes will be required.
- Mix enzymes with a small amount of apple or pear puree. This is important as the acidity of the fruit will aid absorption of the medication.
- Administer with a soft baby spoon.
- If your baby spits out the mixture, gently scoop it back into their mouth until the whole dose is consumed.
- Be sure to wipe away any granules left around their mouth as they can cause ulcers if left on the skin. This can be done with a large cotton tip or small flannel dipped in sterile water.
- Some babies may get nappy rash from using enzymes. A barrier cream applied liberally at each nappy change will help prevent this.

What to Look Out For?

Weight gain is a good indicator of how well the enzymes are working and if your baby is absorbing and digesting their feeds. It is important to learn the warning signs that may indicate that your child is having problems digesting their food.

- Tummy pain and discomfort – in babies this may include squirming or tensing up muscles as well as facial expressions such as squeezing eyes shut or grimacing.
- Excessive smelly wind.
- Greasy, oily poos.
- Diarrhoea and/or constipation.
- Hunger despite eating lots of food.
- Poor weight gain and/or growth.

The effects of CF on the pancreas can also contribute to symptoms such as reflux, cramping, bloating, wind and constipation.

Tips for Using Enzymes Out and About:

Getting out of the house with a new baby can be daunting, especially with enzymes to consider, but this too will get easier with time. Many families pack a cooler bag with the enzymes, soft baby spoon and the apple or pear puree. You can also add a flannel for wiping any enzymes left on their face.

You can make your own puree at home, or puree pouches are convenient, especially when out. However, remember these need to be refrigerated once opened, so ensure you use a cooler bag with an ice brick.

It will get easier as time goes on and you and your baby get used to it.

> *"I put a big whiteboard on the wall to tick off medications and physio to try to keep track. I also wrote daily amounts of salt, enzymes needed for each feed and antibiotic doses when needed too. Having it on the kitchen wall also made it easier for my husband to see what had been done."*

> *"I made up large batches of apple or pear puree every couple of months and would freeze it into small portions, such as in an ice cube tray. I would take one out of the freezer the night before to allow it to thaw out."*

For more detailed information about feeding and enzymes, go to:
www.cfwa.org.au/wp-content/uploads/2018/03/CF-Food-Nutrition-for-Infants.pdf

SCAN ME

Reflux and CF Babies

Reflux is a very common condition among babies and even more common in CF. It is caused by the acid in the stomach rising into the oesophagus causing discomfort for your baby. It can cause symptoms such as an unsettled, crying or fussy baby, excessive spitting up or vomiting, irritability during feeding and sleeping, coughing at night and others.

Mild Reflux Can Be Managed By:

- Ensuring clothing is not too tight around their tummies.
- Feeding your baby in a more upright position.
- 'Burping' longer after feeding.
- Making sure you allow at least an hour after feeding before physio.

Medications are available for severe cases and may be something to discuss with your baby's CF team.

To read our Reflux factsheet, go to:
www.cfwa.org.au/what-we-offer/resources

SCAN ME

Vitamin Supplements

Vitamins are essential for normal growth and function and to help fight infection. As many people with CF have trouble absorbing fat, they often have difficulty absorbing the fat-soluble vitamins A, D, E and K.

VitABDECK is a CF-specific multivitamin that is generally prescribed for people with CF, including infants. Vitamin supplements should be mixed in with apple or pear puree or dissolved in a syringe with sterilised water. To enhance absorption, the mixture should be taken with enzymes and a fat-containing food or drink (breast milk or formula for your infant).

Salt Supplementation

Those with CF lose a lot of salt in their sweat. Some parents even report that their baby's skin tastes salty when they kiss them, or they may have salt crystals on their skin when it is hot.

As a result of this, children with CF usually need extra salt, either added to expressed breast milk/formula or syringed straight into the mouth. As they get older, salt is added to their food and drink as well.

Each baby will have individual salt requirements as their needs will differ depending on factors such as CF symptoms, weight, and the climate you are living in. In WA, salt supplementation is usually required all year round.

Loss of salt can increase the risk of dehydration. This can be serious, especially in babies and young children and can contribute to your child's mucus becoming thicker and stickier.

Signs of Dehydration:

- Fewer/lighter wet nappies than usual
- Salt crystals on the skin
- More concentrated/darker urine in nappies
- Dry skin and lips
- Tearless crying
- Lethargy and drowsiness

If you think your baby is dehydrated and has any of the above signs, try giving them smaller amounts of milk feeds more frequently. If you have any concerns about your baby's nutritional absorption and growth, or dehydration, please speak with their CF team.

How to Protect Your Baby From Infection

Germs

Germs are microscopic organisms that can make people sick. For people without CF, most germs are not a problem. However, these same germs may cause problems for people with CF because they can get trapped in the mucus in their lungs. Some simple steps can be taken to minimise your baby's exposure to germs, including:

- Handwashing with soap and water or alcohol-based hand gel is the easiest and most effective way to stop the spread of germs.
- Avoid people who are unwell. Let your family, friends, school contacts and workmates know about the risk they pose to your child if they visit when they are unwell. CFWA can help with this through school and community education.
- Encourage family members, including siblings, to cough or sneeze into their elbow or a tissue and wash their hands before touching your baby.
- Keep up-to-date with immunisations.
- Make sure you follow the recommended cleaning advice for your child's medical equipment.
- Do not share your baby's medical equipment or eating utensils or cups.

Your child can still do most normal activities. They will be able to go to playgroup, shopping centres, the supermarket and to the playground, however some precautions will need to be taken.

Cross-infection

Research has shown that people with CF are also at risk of sharing germs with each other. This is referred to as cross-infection. For this reason, it is recommended that people with CF do not have close contact with other people with CF, including babies. Precautions will be taken at clinic and in hospital to ensure children with CF are kept apart.

Other Things to Consider

Immunisations

Immunisation is a safe and effective way to protect everyone against preventable illnesses and helps stop the spread of illnesses in the community. For people with CF, immunisation is even more important due to the potentially serious consequences of infection.

Your child should follow the routine immunisation schedule as per the National Immunisation Program. This program is funded by the Australian Government, so these vaccines are provided for free.

Influenza (flu) Vaccine

The influenza vaccine is often referred to as the 'flu needle'. All children with CF should receive this vaccine from six months of age and should have it every year just before flu season. Having this vaccine will not prevent your child from the usual coughs and colds but will help prevent a serious illness.

We recommend that all family members and close contacts also have the annual influenza vaccine to reduce the risk to your child.

Whooping Cough Vaccine

Whooping cough can have very serious and sometimes life-threatening complications for babies in the first six months of life. It is important for babies to have their whooping cough vaccination as per the national recommendations. It is also important for parents and other family members to have their whooping cough booster to protect newborn babies.

For a range of factsheets on infection control, go to:
www.cfwa.org.au/what-we-offer/resources.

SCAN ME

Smoking

Smoking and second-hand smoke (SHS) have been shown to have serious and detrimental effects on the lung health of people with CF.

SHS includes exhaled smoke and smoke that drifts from a burning cigarette, cigar or pipe. People with CF have an even greater risk of complications from SHS exposure as the toxic gases and irritants can aggravate their CF lungs.

Third-hand smoking (THS) is a term used to describe the residual contamination from tobacco smoke that lingers in rooms long after smoking stops. There is growing evidence that THS poses significant health risks.

Children of smokers are especially at risk of THS exposure and contamination because the tobacco residue is present in dust throughout places where smoking has occurred such as the home, clothes, hair and car.

Things You Can Do:

- If you smoke, seek help to quit.
- Insist on keeping your home and car smoke-free.
- Ask friends and family that smoke, not to smoke around you or your child.

To read our Smoking factsheet, go to:
www.cfwa.org.au/what-we-offer/resources.

SCAN ME

CF Health Care Team

PCH has a team of highly qualified health professionals that will help you manage your child's CF. Your team will be working with you and your baby until they reach adulthood and transition to adult care.

You and your child are valued members of your health care team. You have a unique view on how CF affects your child and everyday life.

You can read more about the PCH CF service here:
pch.health.wa.gov.au/Our-services/Respiratory-and-Sleep/Cystic-Fibrosis

CF Care Team Members

Clinical CF Nurses
The CF nurses are the primary contact person for your questions and concerns.

Respiratory Physicians
There are number of respiratory physicians working within the clinic at PCH. When your child is diagnosed with CF you will have one main physician who will oversee your child's care, called a primary physician.

This doctor will be involved in making major decisions regarding your child's care. During your clinic visit your child may be reviewed by another member of the medical team. If any major decisions are to be made, where possible, your child's primary physician will be involved.

Dietitian
The dietitian will work with you to make sure your baby gets the nutrition they need to grow normally. They will teach you about specialist dietary needs for your child, including managing enzymes and salt and vitamin supplementation.

Physiotherapist
The physiotherapist will work with you and your baby to develop an individualised physiotherapy plan, which will change over time. You will see your physiotherapist at clinic appointments for regular review and follow up.

Social Worker
The social worker will assist you with any challenges you may have relating to parenting or managing the CF care of your child. They will also assist with information and resources such as the application for a Health Care Card, Centrelink benefits and the Patient Assistance Transport Scheme (PATS) for country families.

Gastroenterologist
A gastroenterologist is attached to the CF team at PCH and usually assesses your child at diagnosis and then annually. Some children may need to be seen more frequently if they are experiencing gastrointestinal issues.

Clinical Psychologist
The clinical psychologist is available to assist your child with any CF related psychological concerns. You will meet the clinical psychologist briefly as part of your initial education.

Pharmacist
The pharmacist will help you understand your child's medications, including how and when to take them. They will also explain the Pharmaceutical Benefits Scheme (PBS) that offers subsidised medications.

Hospital and Clinic Appointments

Managing CF requires regular appointments with your CF team. At first, appointments will be frequent but as you gain confidence in your child's CF care, and you both settle into a good routine, the frequency of appointments will ease.

Your child will attend CF clinic appointments as needed, including an annual review. However, if they are unwell, they may need to be seen more often.

You should feel confident to speak with any member of the CF team about any questions or concerns you may have about your child's health. They will encourage you to contact them at any time as issues arise.

Contact Details

During Office Hours:

Contact the CF nurses at PCH. They can be contacted by calling the Respiratory Medicine Department on **(08) 6456 0217** or emailing **pch.cf@health.wa.gov.au**. The nurses will be able to offer you advice on management. If needed, the nurse will arrange an appointment with the doctor.

After Hours:

Call the hospital, state that your child has CF and ask to speak to the Respiratory Physician On-Call.

www.pch.health.wa.gov.au

Other Useful Health Professionals

General Practitioner

Your child's general practitioner (GP) is a key member of your healthcare team. Infants with CF need basic medical care as well as CF care. Your GP will take care of some of your child's health needs.

Child Health Nurse

Your child health nurse will complete your child's growth and development assessments and screening and provide immunisation advice.

Cystic Fibrosis Western Australia (CFWA)

CFWA offers a range of services for people with CF and their families. You can also keep up-to-date with CFWA services and events by signing up as a member for free.

Go to our website to join:
www.cfwa.org.au/get-involved/become-a-member

SCAN ME

"Reach out to CFWA. There is always someone there to talk to and are amazing help we've found, and they also connect you to other parents which really helps. They just know what you're going through."

Our Services Include:

Family Support

In WA we have a range of programs which have been developed to support families with CF. This may include assistance with routines through our Calm Kids Happy Families Program and airway clearance support when your child is older.

Social Work

Dealing with the diagnosis of your child's CF can be difficult and can affect your mental health. If you or your partner are struggling, our social workers can provide support and referral to further support as needed.

Education and Resources

We have a range of CF information available on our website.

We also offer education for extended family, day care services, playgroups and other community groups throughout WA.

> *"Involve your extended family or close friends in any available CF education, so that they can learn about CF and how to care for your baby. If you have a few support people available who you trust and who know about CF, this can make things more manageable".*

Subsidies

Various subsidies are available to assist with a variety of CF-related costs.

Regional Support

Country regions are visited by the team at CFWA as required to support members, provide education to schools, community groups and health professionals, and to link up members within their local community. If you live regionally and need support, please don't hesitate to get in touch.

Connecting Up and Staying in Touch

Member Events

We hold a range of member events throughout the year, designed to support family members of those living with CF. These events provide connection and respite and the opportunity to meet other parents and carers.

Social Media

CFWA's Facebook and Instagram pages are a great place to keep up to date with all that is happening at CFWA.

@CysticFibrosisWA

@cysticfibrosiswa

We also have a private Facebook group, CFTalk Parents, for parents and grandparents to ask questions, share advice and make connections within the community:

www.facebook.com/groups/cftalk.parents.

"It is important to identify your support network and to use them and not try to manage to do everything yourself."

E-News

We send out a fortnightly email with the latest information about CFWA services and events as well as general CF information.

Red Magazine

We produce three RED magazines a year, full of member stories, CF news, services and fundraising updates.

Contact Details

(08) 6224 4100

info@cfwa.org.au

The Niche Building, Suite C
11 Aberdare Road
Nedlands 6009

www.cfwa.org.au

For more information about our services, please go to our website or get in touch with us.

Useful Resources

CFWA Website Newborns Page

Our website has a wealth of information for parents with a new baby with CF including information about CF and treatment, member stories, short films and much more

Go to **www.cfwa.org.au/living-with-cf/newborns**

CFWA Website Parents and Others Carers Page

This page is designed to offer support to those caring for someone with CF and share stories of the lived experience.

Go to **www.cfwa.org.au/parents-and-carers**

CFTalk: The Early Years

This video is filmed with members of the CF community in WA and explores the early years of having a baby with CF.

Go to **vimeo.com/416263069**

Baby Steps Cystic Fibrosis

This website was developed by Cystic Fibrosis Community Care in conjunction with parents who have had shared experiences. It includes information about CF, raising a child with CF and emotions after diagnosis. .

Go to **www.cysticfibrosisbabysteps.org.au**

Perth Children's Hospital

PCH have a page of CF specific resources for patients and families.

Go to **pch.health.wa.gov.au/Our-services/Respiratory-and-Sleep/Cystic-Fibrosis/For-patients-and-families**

Useful Definitions

Airway clearance
Airway clearance techniques are treatments in CF that assist in loosening and clearing the thick and sticky mucus from the lungs to help keep the individual healthy and breathe easier.

CF Gene
This gene provides information so that the body can maintain a balance of salt and water in tissues for the production of thin, free flowing mucus.

Constipation
Is difficulty emptying the bowels or infrequent bowel movements and is usually associated with hardened stools, abdominal pain and bloating.

Cross-infection
Cross-infection is the exchange or spread of infection from one individual to another. In CF, cross-infection poses a serious problem and can lead to a decline in health and this is why people with CF should not come within 4 meters of each other.

Dehydration
Losing too much water and salt from the body.

Digestive system
The digestive system is made up of a long, twisting tube which begins at the mouth and ends at the anus. It also includes the stomach, pancreas, and liver.

Enzymes
Are proteins that can assist, cause or speed up a reaction. Enzymes play many roles in our bodies including digesting food and transmitting nerve impulses.

Gene
A set of instructions that decide things such as eye, hair and skin colour.

Germs
Organisms that can cause infections, like bacteria, viruses and fungi.

Heel Prick Blood test (Guthrie Test)
A heel prick blood test is a common procedure for taking a blood sample from the heel of a newborn infant. The blood collected is then tested for a variety of genetic conditions (including CF).

Immunisation
A vaccine given to protect children, adolescents and adults against harmful germs.

Influenza
An acute, highly contagious infection of the respiratory tract, often called 'the flu'.

Infection
The invasion and multiplication of harmful microorganisms (germs) that are not normally present in the body, e.g. bacteria and viruses.

Inflammation
The body's response to an infection or injury. In the lungs, airways become swollen and narrow.

Inherited (genetics)
Personal attributes acquired when parents pass on genetic information in their DNA to their child.

Intestine
A tubular passage connecting the stomach to the anus. This is where digestion of food happens.

Liver
A large and complex organ of the digestive system. Functions include storing blood, creating bile to help with fat digestion, controlling blood clotting, fighting infection and storing iron.

Mucus
A thin layer of protective liquid. In the respiratory system, this liquid helps to prevent germs from penetrating the cells below. In the digestive system, it lubricates a passage for food, as well as protecting the cells.

Pancreas
A gland that sits behind the stomach that secretes enzymes which help to digest food. The pancreas also produces a hormone (insulin) that helps the body use and store sugar for energy.

Reflux
Gastro-oesophogeal reflux is a common condition in children and adults with CF. Stomach acid rises up into the oesophagus causing discomfort and pain known as heart burn.

Respiratory system
The respiratory system consists of organs such as the nose, pharynx, larynx, trachea, bronchi and lungs that allow us to breathe and exchange oxygen and carbon.

Sweat glands
Tiny structures in the skin that secrete sweat. Their function is to keep the body at a normal temperature.

Sweat test
A test that measures the concentration of chloride that is lost during sweating. This test is used to confirm a diagnosis of CF.

Vaccine
A preparation that helps to improve immunity to a particular disease.

CYSTIC FIBROSIS Western Australia

Disclaimer
This publication has been prepared solely as a general guide for use by patients and prospective patients in relation to information given to patients in hospitals managed by the Government of Western Australia and the Department of Health.

Although all due care has been taken in the preparation of the publication, it is only to be used as a guide and is not a substitute for advice from your specialist or other medical expert who is treating your child.

Cystic Fibrosis Western Australia
The Niche, Suite C 11 Aberdare Rd
Nedlands, WA 6009

P: (08) 6224 4100
W: www.cfwa.org.au
E: info@cfwa.org.au