Cystic Fibrosis Trust

Trusted Information Creator
Patient Information Forum

Cystic fibrosis diagnosis and your baby

A guide for families

Contents

A huge thank you to all the families and cystic fibrosis health professionals who contributed to this booklet. They have generously shared their time, stories, experiences, and expertise, and we are extremely grateful to them.

What is cystic fibrosis?

Cystic fibrosis is a genetic condition affecting more than 11,000 people in the UK. You are born with CF, and will have the condition all your life. You cannot catch it.

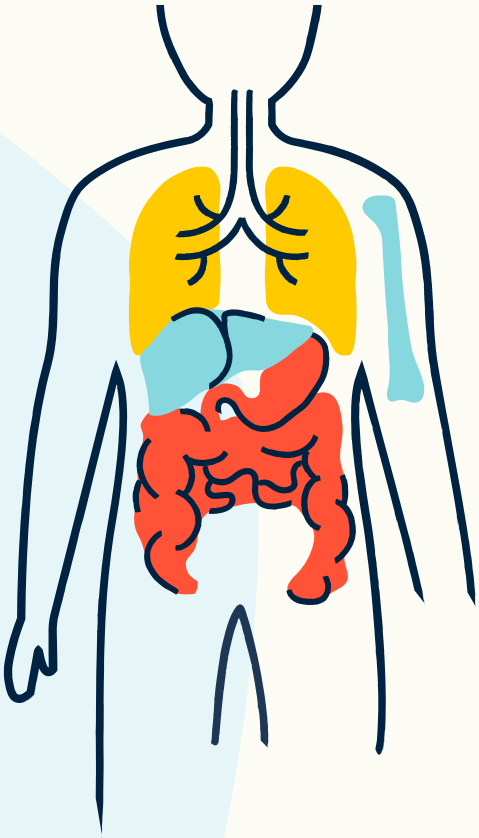
The CF gene makes a protein that controls the movement of salt and water in and out of the body's cells. In someone with CF, this gene is faulty (also called a mutation or variant). This means the protein is abnormal or not there at all. As a result, the body produces thick, sticky mucus that affects the lungs and digestive system.

How does CF affect the lungs?

We all have a small amount of mucus in our airways which helps keep them healthy and free of infection. In people with CF the mucus produced is thick and sticky. Over time, this makes people with CF more likely to get airway infections, which can lead to more mucus and inflammation in the lungs. Treatments are getting better at preventing this mucus build up and keeping the lungs healthy.

How does CF affect the digestive system?

Most people with CF cannot digest food very well as their pancreas does not produce digestive enzymes. This means that newborn babies with CF can fail to gain weight, even though they might be feeding well, and have more regular wet and dirty nappies. They can be unsettled until their digestive issues are in a treatment routine. You can read about treatments to help your baby digest food on page 11.



I've just found out my baby has cystic fibrosis

For many families, when they find out their baby has cystic fibrosis (CF), the news can come as a great shock. The birth of a new baby brings with it a mixture of emotions, which can also be true for parents when they find out their child has CF – you may be feeling sad, worried or angry, or you might feel relieved that you now have a diagnosis if you've been worried about your baby's health. Everyone has their own response, and there's no right or wrong way to feel.

You may feel overwhelmed at the information that's being shared with you so early on in your child's life.

Or you may be thinking about what having CF will mean for your child and your family as they grow up.

Every parent's experience of being told their child has CF is different.

However you're feeling, you're likely to have lots of questions.

This booklet gives an overview and some information to support you through these early days following diagnosis.

"Advice I would give to any new parent is: take one step at a time. One day at a time. The information you are given in the beginning can be so overwhelming and a lot to take in. The [CF] community is out there – reach out when you're ready."

Holly, mum to Amelia, age 2

"When I was sitting in the hospital, I was handed some info a nurse had printed out for me about CF and I remember reading a mother's story. She said that she lost the first year of her child's life because CF had consumed her. I remember being determined not to let that happen, and the sad thing is, I did. The first 18 months of my daughter's life, I struggled, and I grieved. It's my biggest regret. Try not to let this happen because you never get that time back."

Jade, mum to Penelope, age 7

Jade and Penelope

It might be tempting to look for information about cystic fibrosis online or on social media, but this can be misleading, out of date and may not be relevant to your child.

We are Cystic Fibrosis Trust. We help families give their child the best possible support every step of the way, and we're here for you.

If you have questions or need support, talk to your CF team, contact our Helpline and visit our website at **cysticfibrosis.org.uk**

Letter from the heart

Laura, mum to Jack, age one, describes her feelings in a letter

cysticfibrosis.org.uk/newdiagnosis

"When the doctor was telling us what cystic fibrosis is, I stopped her and asked what this word means in Polish, because I had only been in England for two years and the medical language was foreign to me. My midwife translated it for me and then it all started... I went to the kitchen hugging Igor and crying loudly. I asked myself: 'Why?'."

Marta, mum to Igor (who has CF) and Wiktor, both age 6

"At first we were shocked as this was the first time we'd heard of the condition."

Mithun, dad to Dhyuti, age 8 months

Testing for CF

In the UK, every baby is offered newborn bloodspot screening, also known as the **heel prick test**. This usually happens when they're around five days old. It involves taking a blood sample to find out if your baby has one of nine health conditions, including cystic fibrosis. As a result, CF is usually diagnosed shortly after birth, but sometimes a diagnosis can take longer. Sometimes CF might be diagnosed before birth through genetic testing. Whether your baby is well or showing signs of being unwell, when you get the diagnosis, it can come as a shock.

Sometimes CF is suspected before diagnosis. This might be before birth, through ultrasound scans during pregnancy, or shortly afterwards.

Your doctor might have suspected your baby has CF if they have an intestinal or bowel obstruction (blockage) called meconium ileus (MI), or if your baby isn't growing as expected – this is called 'failure to thrive'.

You may have had a home visit from a CF healthcare professional or the news may have been shared with you at the hospital.

How you find out about your child's CF can have a big impact on how you feel about the diagnosis. You might have found out quickly or had to wait. Diagnosis stories and experiences can all be different, but all can be similarly emotional, and your experience is something that's likely to stay with you.

"The 20 week prenatal scan showed an echogenic bowel, so we were sent for genetic testing and were found to be carriers. Natalya was born with meconium ileus and the official diagnosis was given one week after Natalya was born, via a heel prick test."

Natasha, mum to Natalya age 3

If a baby is thought to have CF, a **sweat test** is usually done as part of the testing process.

The gene affected by CF controls the movement of salt and water in and out of cells. People with CF lose a large amount of salt in their sweat. The sweat test measures this.

It is done by collecting a small amount of sweat from the arm or leg. This is not painful.

The results are usually available quickly, and sometimes you will be given the sweat test results later the same day. If not, the person doing the test will let you know when the results will be available. The test may need to be repeated if not enough sweat is collected.

You can read more about the sweat test at **cysticfibrosis.org.uk/sweattest**

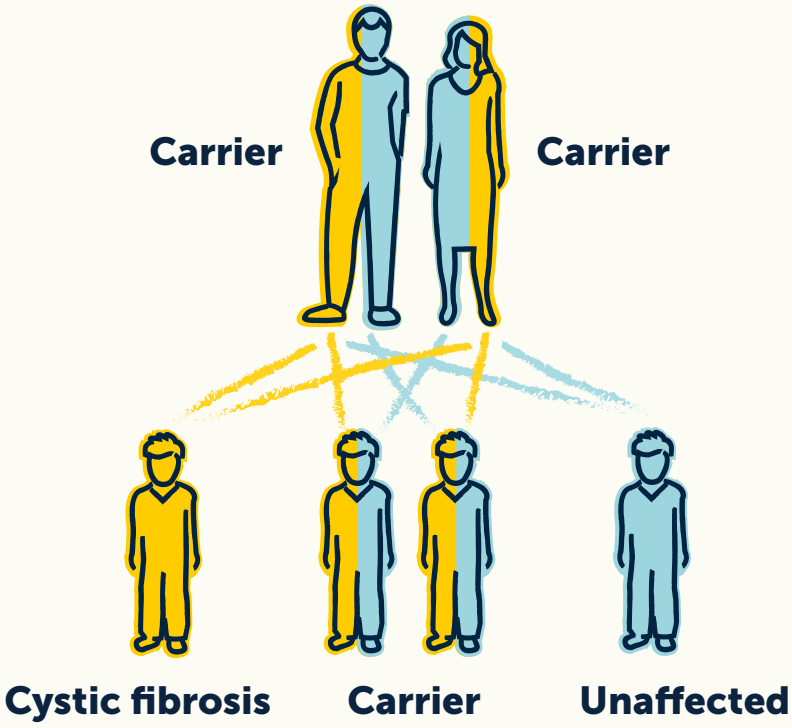
For further information, videos and other resources about diagnosis, including families' stories, visit **cysticfibrosis.org.uk/newdiagnosis**

Why does my baby have cystic fibrosis?

Cystic fibrosis is a genetic condition, and a baby is born with CF if both parents have a variant of the cystic fibrosis gene. We have two copies of each gene, one set we inherit from each parent. To have CF, both CF genes need to be affected.

If only one copy of the CF gene is affected, then the person is a carrier. Most people will not know they are carriers, since as a carrier you are unlikely to have any CF symptoms. Around 1 in 25 people carry a CF gene variant. If both parents carry the CF gene, there is a one in four chance that their baby will have CF. This is the same for each pregnancy.

Find out more at
cysticfibrosis.org.uk/cfcarriers



What can I do to help my baby right now?

The arrival of a new baby is a special time for you and your family. We are here to support you as you welcome your new addition. Spend time together, give them love, try to build a routine that works for your family, and take as much support as you can from those around you and your CF team. You will have time and support to adjust to the diagnosis, and looking after yourself is important to make sure you're able to look after your baby. You'll be learning as you go, and no one expects you to know everything straight away.

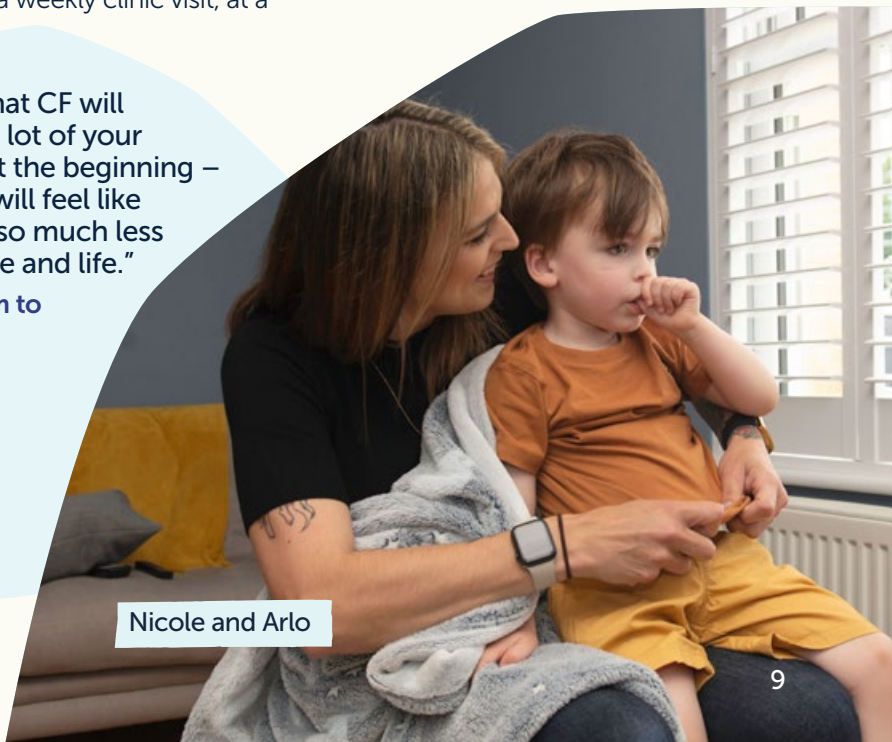
Your CF team will help you learn all you need to know about CF. This might be at a weekly clinic visit, at a home visit, or they might invite you to an education visit. They will explain how the team works and how they can support you.

Focus on making your baby's treatment part of your daily routine and family life. Family life as you know it can continue and, in time, you will get used to CF being part of it.

Your CF team will talk to you about the best treatment for your baby, based on their needs. This might look different to another child's, as everyone with CF is different. For support with understanding this, talk to your CF team or contact our Helpline.

"It's okay that CF will consume a lot of your thoughts at the beginning – one day it will feel like it takes up so much less of your time and life."

Nicole, mum to Arlo, age 3



Nicole and Arlo

Families experience and cope with CF in different ways. The journey is not predictable, and some children will be healthy whereas others may have more symptoms.

CF means that your child will need to take some medicines and do regular physiotherapy to help keep them as healthy as possible. This might seem overwhelming at first, but doing these treatments from an early age will help your child stay well. Many parents find that this soon becomes a routine part of day-to-day life.

Your baby has CF, but also the same needs as all babies – they will eat, sleep and cry, and will need love and cuddles, just like any other baby.

Medications for keeping the lungs healthy

As CF can affect many different parts of the body in many different ways, your child may need to take a number of different medicines.

Inhalers and nebulisers

Many medicines for CF are inhaled (breathed in), using an inhaler or nebuliser.

Inhalers are devices that are used to deliver medication to the lungs either as a dry powder or as a spray.

Nebulisers change liquid medication into a mist so they can be breathed into the lungs.

They are used daily to help open up their airways, treat infections, and help thin the mucus to clear the lungs and prevent infections.

Antibiotics

Your baby might need to take antibiotics, to prevent, treat or control bacterial infections.

Modulators

A newer type of medicines called CFTR (cystic fibrosis transmembrane conductance regulator) modulators are becoming increasingly available. You might hear them referred to as just 'modulators'.

While conventional CF treatments target the symptoms of cystic fibrosis, these

drugs tackle the underlying genetic variants that cause CF by helping to make the CFTR protein work effectively.

They do not cure the condition, so routine CF treatments are still needed. Currently, not everyone with CF is able to benefit from modulators – there are some age restrictions and some gene variants do not respond.

Your CF team will be able to explain whether modulators, and other medications, are suitable for your child.

Diet

Good nutrition and weight gain are very important for babies with CF to stay healthy. Your baby may need to take pancreatic enzyme supplements (for example, Creon®) with their milk feeds (and later with solid food). These replace the digestive juices which are blocked inside the pancreas in CF, so your baby can digest their food and milk. If their food and milk is not being properly digested, your baby is likely to have frequent loose, greasy stools in their nappy.

Our leaflet **Pancreatic insufficiency and nutrition in cystic fibrosis (babies)** has information on giving enzymes to breast and bottle-fed babies, but your CF team will also support you.

Creon® contains pancreatic enzymes from pigs. If this concerns you for religious, cultural, or lifestyle reasons, you might like to speak to your religious leader or appropriate organisation. At present there is no alternative.

"Sometimes there are no alternatives to medicines containing animal-derived ingredients. The Vegan Society strongly recommends that people take medication that is prescribed to them."

The Vegan Society

Your dietitian will be able to support you when the time comes to move your baby onto solid food (weaning). Some people with CF may need to eat more calories than someone without the condition. They may also need to take vitamin supplements.

We have a series of leaflets on CF and nutrition, which give information on topics such as digestion and weaning at **cysticfibrosis.org.uk/nutritionleaflets**

"After diagnosis, when the treatment started, I could see the slow improvements and I was happy with it."

Fajana, mum to Khadijah, age 14 months

"Sammy took a feed during the diagnosis and they gave him Creon® in the clinic. No other medication has been as dramatic as this. From the first day on Creon®, he seemed much more settled and comfortable after feeds. He'd had seven weeks of not being sustained by his feeding. Then at diagnosis, with the start of Creon®, it all changed, and feeds nurtured him. Made him comfortable, full and happy and able to sleep too. This was completely different to how he was before Creon®. The difference was huge."

Juliette, mum to Sammy, age 9

Physiotherapy

CF can cause mucus to build up in the airways. This makes people with CF more likely to have airway infections which can damage the lungs.

To keep the airways clear of this mucus, chest physiotherapy exercises (also known as 'airway clearance techniques') will be recommended to you by a specialist physiotherapist in the CF team. Every baby and child will have their own personal physiotherapy programme and your physiotherapist will show you how to do this at home.

Parents have told us that it can be helpful to try to make physio fun and like a game, even from an early age; for example, you can bounce gently on an exercise ball while holding your newborn baby and supporting their head.

Doing physio with your baby can be tricky as they might cry, wriggle or not want to do it. Your CF team can give you advice on things you can do to make it easier. As your child grows older use toys like trampolines – children love to bounce!

We have a series of leaflets on CF and physiotherapy, including Airway clearance for babies and young children and Bubble PEP, which can be found at **cysticfibrosis.org.uk/physioleaflets**

Physical activity

Building physical activity into your life is important and has huge benefits. Being physically active is really good for your child's lungs, and moving your body can help you look after your mental health and wellbeing too.

Children are more likely to be physically active if their parents are active, and talk positively about it. Fun family activities – a walk, playing at the park, playing football, riding scooters or bikes – will be good for you all, giving the whole family the opportunity to spend time together and bond.

Healthy lungs

It's natural for all parents to want to protect their baby and you may feel this more strongly because your baby has CF.

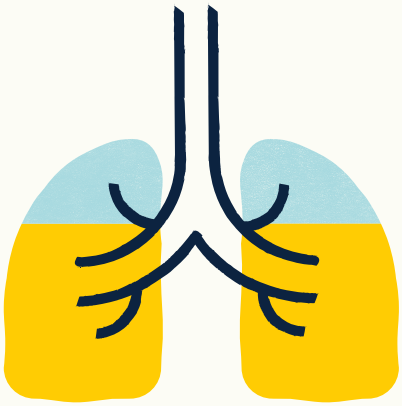
There are some bugs (such as some bacteria, fungi, and viruses) that can potentially harm the lungs of people with CF, and these are common in certain places such as damp environments, stagnant mud, hot tubs, and stables (because of horse manure).

There are also some bugs that people with CF may carry in their lungs which could be harmful to other people with CF. This is known as **cross-infection**. This is why people with CF are strongly recommended not to meet in person. This can be isolating for new parents.

"CF can feel quite lonely at times, having to explain things to friends and family, and it can be frustrating at times. But you know your little ones, and you do what's best for your family."

Holly, mum to Amelia, age 2

Some parents have told us that, in the early days, they felt anxious about their little ones picking up infections. However, over time, they sometimes reconsidered what 'risks' are worth taking to enable them all to have a fulfilling family life. For most families, they can enjoy most things that other families can, sometimes with some adjustments.



It can be helpful to think about balancing a child's physical health needs with their thinking and reasoning, social, and emotional development. Your CF team will support and guide you in making these decisions.

Most children with CF can go to nursery or another early years setting, which can be good for their development and wellbeing. In this environment, they will pick up colds and coughs like all children do. Children with CF have normal immune systems and will fight off these viruses. They may, however, need extra antibiotics.

It's important that your child has all the usual vaccinations offered by the NHS, including flu. Your GP or health visitor will let you know when these are coming up or you can visit the NHS website and search for 'vaccinations'.

What will my baby's future be like?

While every child's needs and abilities are different, you can expect your child to enjoy a childhood that's as full and happy as any other child's – playing, making friends, enjoying sports and leisure activities, achieving at school and having fun!

Cystic fibrosis does not affect brain development so children with CF attend nursery, preschool and school in the usual way and can go on to further education, as many young people do.

They'll need time off to attend CF clinic visits and they may be off sick if they have an infection and need to recover. Schools have guidance in place for this and should be very supportive, and your CF team can also offer guidance and support for the school.

We have resources to support your child at school, including information for teachers.

With the right support and treatment, there are endless life, education and career options that will be open to your child as they grow up. Your child's CF team can also offer support with their education and work opportunities. Cystic fibrosis can affect fertility, but there are rapidly growing numbers of people with CF having families of their own.

"Enjoy your newborn and keep planning that big, bright future you want for them."

Jade, mum to Penelope, age 7

"Today Igor is a Year 1 student, he has a wonderful class and teachers. He has many friends and is a very popular child. He is curious about the world and himself. He is aware of the disease, he started asking his first questions two years ago. The whole class already know about his CF, and at birthday parties before they always ask him if he has taken his meds before they start to eat – it's so touching."

Marta, mum to Igor (who has CF) and Wiktor, both age 6

Marta with Igor and Wiktor

Advances in CF treatments

In recent years there have been fantastic advances in research. These have led to new and better treatments for CF, so there is good reason to be hopeful about the future. There are challenges and compromises with CF, and until a cure is found your child will always have it, but CF care is improving all the time, and there is every reason to be positive.

To learn more about research we fund, visit **cysticfibrosis.org.uk/research**

Will my child have a 'normal' life expectancy?

Your CF team are there to support you and answer your questions if you feel that you want to explore this topic. They are best placed to offer emotional support and up-to-date information.

Life expectancy has increased greatly. Today, most people with CF will have full childhoods and enjoy much longer, healthier adult lives. An increasing number are having their own families.

There are lots of articles about life expectancy online, and it's important to know that such statistics are averages and cannot be applied to any one person– everyone is different. Some information you read about CF may also be out of date.

Improvements in CF care and treatment give us hope that most babies born with CF today will have a life expectancy similar to someone without CF.

If you would like support in exploring this topic, you can speak to your CF team about access to a CF psychologist.

"I've just finished Year 10 so I'm halfway through studying for my GCSEs and will sit them next year. I then want to go to Sixth Form and then University to study Medicine and become a paediatrician. I love acting – anything theatre-related really! I also like writing and reading. I've taken part in Girlguiding, book clubs, sports teams, YAG and loads of school productions! I don't do a lot of physio right now – only when I really need it. It's mainly tablets and exercise. I've got a dog called Woody and a tortoise called Minnie!"

Tilly, 15, who has CF

Watch our video of Tilly, 15, talking to her parents about when she was diagnosed at 10 days old.
youtu.be/_rFhXSgfYQ0

When I grow up...

Read about some of the different career paths that members of our Youth Advisory Group (YAG) are pursuing at **cysticfibrosis.org.uk/whenigrowup**

How can I look after my mental health and wellbeing?

Your health and wellbeing are so important. Looking after yourself not only helps you to cope with this new situation, but also to enjoy your new baby.

Parenting a child with a medical condition means that there are extra things that you need to do to meet your child's healthcare needs, on top of the usual challenges of parenting. At times, it's common to feel overwhelmed, exhausted or have feelings of anxiety or depression. Having a child with CF affects the whole family, so talk to your relatives and friends about how you're feeling.

Some parents have told us that while they feel they coped fairly well at the point of diagnosis, they struggled later on; for example, when their child was 12–18 months old. There is no timeline of how you should feel, and for how long. Everyone reacts differently, and we'd encourage you to seek support whenever you feel you need it.

"We've noticed we have three good days in a week and then two or three bad days because she becomes ill quite easily."

Chand, dad to Khadijah, age 14 months

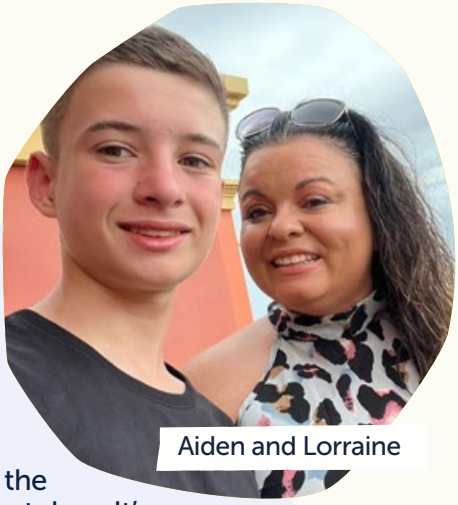
We know from listening to parents' experiences that you might feel up and down, and that the difficult moments can arise when you least expect them. Please know that this is normal and okay.

You can get support from your CF team, Cystic Fibrosis Trust or whoever you feel most comfortable contacting. You'll be met with kindness and understanding. Talking openly about your feelings is an important part of looking after your mental health and wellbeing. Professionals can offer a listening ear, a shoulder to cry on and advice.

If you're struggling after the birth of your child, speak to your community midwife, health visitor or GP. You can also get support from your CF team, and Cystic Fibrosis Trust's Helpline.

"As a new dad I found one of the trickiest areas was knowing how to help. Mum's role in those early days is often much more defined than your own. This loss of agency feels even greater when your little one is diagnosed with CF. Try to forget about the things you can't control with the diagnosis, and focus on those that you can. Be the parent who does the physio. Be the one who prepares the meds. Be the one to go to the pharmacy and befriend them! In doing this you gain some control of the situation, give your partner some much needed space, and start to redefine your outlook. You are needed more than you'll probably ever understand – start to believe it."

Ed, dad to Leo, age 6 months



Aiden and Lorraine

"I go to the gym most days. It's my release, my 'me time' and I've met new friends there."

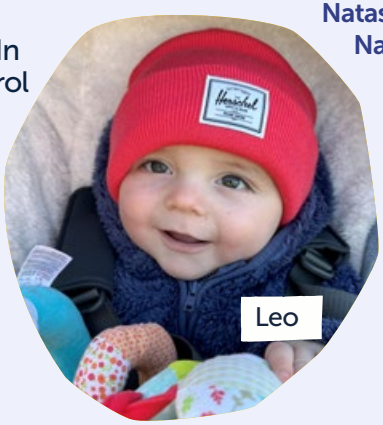
Lorraine, single mum to Aiden, age 13

"If your team has a CF psychologist, talking to them helps ease the mental pressure that is building up."

Mithun, dad to Dhyuti, age 8 months

"Try to make time to still do things as a couple, whether this be a 'date night' after the bedtime routines, making something nice for dinner, watching some rubbish TV, and just enjoy each other's company."

Natasha, mum to Natalya, age 3



Leo

"On the day of Arlo's diagnosis, my husband and I made a promise to each other that if we were having a bad day or needed to have a cry, then we would come and find each other and face it together. In the first year, we found this to be incredibly helpful as we noticed that we were very rarely struggling at the same time, so it allowed the one of us who was in a better headspace to support the other person through it."

Nicole, mum to Arlo, age 3

"We dealt with it differently. My husband was positive. I tried to make it seem like I was positive, but inside I was consumed with worry and dread. Communication is the absolute key here. Talk to each other. Cry together. Be angry. But be happy too."

Jade, mum to Penelope, age 7

"Find a hobby or an interest; work out, go for a walk to release stress, anger, pain and let off some steam. Try meditation, yoga, Pilates, swimming etc."

Sean, dad to Noah, age 4

Siblings

If your new baby has an older sibling, it's likely that your older child will still expect the same routine and attention. It can be hard for older siblings to deal with a new arrival, along with the additional attention that CF may bring. Encourage your other children to share their feelings with you and make sure they feel included in their new sibling's life. Watch together our video for children to help them understand their sibling's condition. **cysticfibrosis.org.uk/childrensvideo**

Sisters Leah and Pia today and as children

"They understand that their sister has a health condition and they look after her."

Fajana, mum to Khadijah, age 14 months

If you have any questions about genetic testing or how to support your children without CF, your CF team will be happy to help.

Support networks

Remember that the people who care about you would like to offer you help and support. Ask them when you need help, not just for your baby but for you too – there will be other times when you can repay the favour. Cooking a meal, a chat over a coffee or taking your other children to school are all things that will help you and allow them to show you that they care.

Not everyone will have friends and family close by to rely on for support. It's worth checking if there are any groups or charities in your local community who can be of help or looking into your Local Authority's Local Offer or Children's Services on your local council's website.

"We had fantastic support. Our parents and best friends, even now, are amazing. My husband isn't a huge talker but every now and then, on those date nights, we talk together. I do get great comfort in talking to my mum and my best friend. They have witnessed our journey since day one and they understand me. Find your person or people."

Jade, mum to Penelope, age 7

"Always ask family or friends for help – even if it is just to watch them for an hour, so you can get a bath, have some sleep and a break from the CF routine. Show them how to do things like give Creon® or do physio or nebs."

Natasha, mum to Natalya, age 3

Visit **cysticfibrosis.org.uk/newdiagnosis** for more information on sharing the news with friends and family, and how they can support you.

"I didn't understand it at first, but I came to all the appointments with her, and ended up taking care of her together with my mother when it came to treatments. I was also being tested for it and carry the gene, so it was important for me to understand it too. She has achieved so much; she didn't let it stop her from following her dream job, travelling, and now she is getting married. Having to watch her take all those tablets and trying to make a young girl understand why they were important was hard. But it also strengthened our bond because we have done it all together."

Leah, whose sister Pia, 21, has CF

Single parents

Looking after a child with a medical condition can be exhausting and isolating, and if you are a single parent you might find there are extra challenges, but you are entitled to support and might be able to get financial help.

Where parents are separated, it can really help for both parents, where possible, to be involved in the child's CF care. Some single parents have found it really valuable for a grandparent or other trusted friend/ family member to understand what's involved in day-to-day care of a child with CF, so that they can step in and provide support if needed.

"CF has meant I've spent more time with him and been at home with him. Now that he's older, we go to the gym and concerts together – we're so close."

Lorraine, single mum to Aiden, age 13

"I didn't return to work until Olivia went to school. This meant we spent lots of quality, one-on-one time together. When Olivia was younger we did physio twice a day and I think this physical contact strengthened our bond. We love to travel together, we have amazing times and we're still very close.

"I took my aunt to all Olivia's CF appointments. It's so useful to have someone else there to support you and help with the practical things like finding parking. We've always tried to make a day of it when we go to clinic – we'd have lunch out and Olivia would have a treat, like a sticker book. She never complained about going to her clinic appointments!"

Jane, single mum to Olivia, age 20

Gingerbread is a charity that supports single parents. Find out how they might be able to help you by visiting **gingerbread.org.uk**

Working and financial support

It can be challenging to juggle working with looking after a child with CF. Unlike other children, time will need to be spent on their treatments and care, including going to clinic appointments. Your CF team can support you to teach people like childminders and nursery staff who look after your child how to give some of the CF treatments. Some parents have told us that working flexibly can help you to manage this. For more information and support visit **cysticfibrosis.org.uk/employment** or contact our Helpline.

Managing CF and treatments can be expensive. We can support you with applying for benefits, accessing grants and other ways you can ease the financial burden and increase your household income. Contact our Helpline for more information. You can also speak to your CF team about access to a social worker who can support you with this.

"Share the baby's CF condition with supervisors or colleagues. There might be cases when you will have to be off work for longer than expected. Setting the expectation at work will help."

Mithun, dad to Dhyuti, age 8 months

"It's changed my whole career plan as I had to work part-time to be around for my son. I claim DLA and Carer's Allowance. Money is a big worry for me."

Lorraine, single mum to Aiden, age 13

Natasha and Natalya

Read Natasha's blog about how she balances working with having a daughter with CF at **cysticfibrosis.org.uk/natasha**

Finding childcare for your child while you work can be an exciting and daunting time for parents. We have information on how to make the transition as smooth as possible, including infection control, diet management and building your relationship with the childcare provider. Your CF team can also support with this. See our booklet **School and cystic fibrosis: A guide for parents from pre-school to primary** at **cysticfibrosis.org.uk/school**

Nursery days

Watch our video to see how his parents and the staff supported Arthur, age 4, with starting pre-school: **youtu.be/O8zjdGZql88**

I have some questions...

Parents have told us that following their baby's diagnosis they had so many questions. Here, we've shared some of their top questions and answers to help you. Remember, our Helpline and your CF team are always happy to answer any questions you have.

It can be helpful to keep a notepad and pen by your bed to note down anything that is playing on your mind at night. You could also make notes on your phone, or draft an email to the CF team.

Q: Can we travel?

A: Yes! There are things you can do to make travelling with a child with CF easier. Being organised is key. Your CF team will be able to advise you on any things you need to consider or take with you. Travel insurance is essential – our Helpline can give guidance on finding insurance providers.

Q: Can we have pets?

A: Usually, so long as good hygiene is maintained. This might include keeping your pets clean, washing hands after touching pets, and not letting pets lick faces or sleep on your child's bed. If you have smaller animals, you might restrict your child from cleaning out cages or changing pet bedding. Your CF team will be able to advise you.

"As soon as we came home with our daughter, we felt overwhelmed by everything – was it ok to take her for a walk? We have a carpet, should we change to hard flooring?"

Mithun, dad to Dhyuti, age 8 months

Q: Is my baby at risk of infection from the environment?

A: The infection risk posed by the environment is often a concern of parents. There are certain environments, such as mud, stagnant water, rotting vegetation and hay that harbour bacteria and fungi that can be harmful to children with CF.

This means activities like playing in mud, sandpits, fallen leaves or puddles might be risky for a child with CF, but unfortunately there's no list of what the exact risks for each activity are.

This means that parents will need to think more carefully about their child's exposure to these risks and what they feel comfortable with, ideally with input from the CF team. This is a very personal process which can change over time and will depend on many things.

Washing hands and equipment will always be important and other adjustments can be made to minimise the risk.

Q. Can we go to baby groups?

A. Yes – make sure you let the group leader know that your baby has CF in case there is another baby in the group with the condition. Be mindful of which activities you're happy for your baby to be exposed to and make sure you're minimising risk by washing yours and your baby's hands, using antibacterial wipes or hand gels and not sharing equipment or toys with other babies. Baby groups can be an excellent way for your baby to socialise and learn about the world, and for parents to meet each other.

Q. We would like to have more children – will they have cystic fibrosis?

A: If you and your partner are thinking about another pregnancy, you'll be able to access support from a genetic counsellor before you get pregnant. They can help you to understand more about your genetics and the options you may have. You can be referred to a genetics counsellor by your GP and CF team.

"There are so many things around the house and in day-to-day life with a baby that we have to approach a little differently or be a bit more careful of. It doesn't stop us – after all, our main goal is to make sure that CF does not define our little ones or stop them from doing the things that they want to do. But we just have to manage some of the risks."

Nicole, mum to Arlo, age 3

"As a parent you want to do everything to fix it. And apart from taking all the advice from healthcare professionals and doing all the things they tell you – you can't fix this. You can help though. Fundraise, make it fun. Involve your friends and family. Try to be the same parent with your child that you planned to be. Love them the same. Hug them the same. They have CF but they are still that perfect little dream that you wished for."

Jade, mum to Penelope age 7

Some parents choose to explore IVF for any subsequent pregnancies – for example, PGD (pre-implantation genetic diagnosis) is performed as part of an IVF cycle to see if the embryo has CF. Our Helpline can provide information about genetic testing.

Find out more at **cysticfibrosis.org.uk/carriertesting**

Q. Will my child be able to have children of their own?

A: The number of people with CF who are having children is increasing every year. Although most men and some women with CF will experience some fertility issues, many people with CF are able to have children, and your child will have family planning options to explore if they make the decision that they would like to have a family in future.

Find out more at **cysticfibrosis.org.uk/familyplanning**

Parents' top tips

We asked a group of parents of children with CF to share some of their top tips.

1. **Ask for a cough swab**
   If you're concerned about your child's health, call your CF team and they will advise if a cough swab is needed. The cough swab will help the team find out if there are any bugs growing in the lungs, and will help guide any further treatment, such as antibiotics.
2. **Be assertive**
   Don't be afraid to be firm with people about what makes you comfortable. If you don't want to go to the wedding because another guest has a cough, don't go!
3. **Make a list**
   Create a checklist of items to put in your bag when going out.
4. **Carry a notebook**
   Take a notebook to your appointments and write down everything your CF team says. You can also use it to write down questions you want to ask before you go.
5. **Give Creon® more easily**
   When your baby is eating solids, you can give Creon® with apple purée – either add it on top of the spoon of apple purée or mix it well so that it can be swallowed more easily.
6. **Get creative with physio**
   Make physio fun! Bounce on a gym ball, use nursery rhymes and music, do it while they watch their favourite tv show (even baby sensory videos when they are very young), and get the whole family involved.
7. **Choose the right gym ball**
   Gym balls are available in different sizes, so make sure you are using the most suitable one for your height and build. This will help to look after your own back when doing physio with your baby.
8. **Be prepared**
   Always have nasal sprays and nasal aspirators ('snot suckers') at home.
9. **Make a Creon® chart**
   If someone else will be looking after your baby, you could make them a chart with a table to show how much Creon® to give your baby with food. For example, X gram(s) of fat = X scoop(s) Creon®.
10. **Collect a urine sample more easily**
    For a urine sample, put a small amount of cotton wool in the nappy to catch urine in babies or toddlers still wearing nappies.

Check with your CF team before trying these parents' tips to ensure they are safe and appropriate for your child.

What support is out there for us?

It's important to remember that you will know your child best, so if there is ever anything you're concerned about, contact your CF team.

Your CF team

You should already be in contact with someone from your CF team, and gradually you'll meet everyone. They will be the key partners to support you with your baby's care.

For many families, the CF specialist nurses will be key healthcare workers – responsible for coordinating care and support on behalf of the CF team. They will answer any questions you have, guide you on how to give your baby medicines and organise clinic appointments.

"I'm very used to reading emails from new parents when I arrive at work that they have sent in the early hours of the morning, when they have a question that's keeping them awake at night."

CF nurse

Your CF team will be a source of support as you're finding out more about CF, discovering what works best for your child and family, trying out new approaches and adapting as your child grows and their treatment routine changes.

Your child will have a CF team that they will see regularly, especially in the first year of diagnosis. How often you go to clinic will depend on your child's health, and you may have home visits and phone calls in-between clinic visits too.

The team includes several different health professionals and can include doctors, CF specialist nurses, dietitians, physiotherapists, pharmacists, psychologists and social workers.

They are experts in CF and will be able to advise you on any questions or worries you have about your baby – whether you're struggling to tell the difference between a wet cough and a dry cough, or you're unsure of how to give your baby a prescribed antibiotic.

"I relied on the CF nurse as a point of contact for all support."

Tiffany, mum to Joseph, age 5

"The support of the CF team, along with Cystic Fibrosis Trust is more than I could have asked for."

Mithun, dad to Dhyuti, age 8 months

Your local pharmacy

It's useful to establish a good relationship with your local pharmacy staff. They will deal with many of your baby's prescriptions and it is helpful if they, over time, are able to understand what medications need to be issued and why.

Many parents have emphasised the help that an understanding pharmacist can offer. They can also be sympathetic to your personal circumstances and will help if they can.

One single mum of a child with CF explained to us that she was once told by her pharmacist that her child's prescription would be ready at 8pm that night, but once she explained that she was parenting alone and her baby should be in bed at that time, they rearranged future collection times.

"I've had to learn to be more assertive. I explain my circumstances and then I'm offered other options."

Lorraine, single mum to Aiden, age 13

Some medications will need to be provided by the hospital, or via a homecare medicines delivery service that will deliver them to your home.

Your GP

Although your child will receive their CF care at a specialist CF centre, like all families you will also have contact with your local GP.

It's helpful to try to build up a good relationship with your practice so they understand you and your baby's needs. Sometimes your local practice may not have had experience dealing with patients with CF and so your relationship may need to be more of a partnership, with you sharing your CF knowledge and experience.

Cystic Fibrosis Trust

New diagnosis information and support emails

We're here to support your family every step of the way. If you would like to hear from us regularly, you can sign up to receive our information and support emails by visiting **cysticfibrosis.org.uk/newdiagnosis** and clicking on the email sign-up button.

We'll send information to support you throughout your baby's first year, including signposting to information and practical support, services available from Cystic Fibrosis Trust, and tips and guidance from other families and CF professionals.

Helpline

Like all parents, you'll be learning as you go – and it might help to talk to someone who understands CF. Contact our Helpline for a listening ear and information by calling **0300 373 1000** or **020 3795 2184**, Monday–Friday 10am–4pm. You can also email **helpline@cysticfibrosis.org.uk**, message us on Whatsapp on **07361 582053** or chat on our socials.

Find out more at **cysticfibrosis.org.uk/helpline**

Information

We offer free, balanced information about all aspects of life with CF, both on our website and in our information resources.

Along with the advice from your specialist CF team, our online content and publications can help you make informed decisions about your child's lifestyle, treatment and care.

All our information is written and reviewed by experienced information and health professionals.

To order, visit **cysticfibrosis.org.uk/information** or contact our Helpline.

Financial support

Cystic fibrosis can bring financial worries, but support is available.

We can give expert advice to help you find your way through the benefits system and understand how you can boost your household income, to make sure everyone with CF has the basics they need to stay as well as possible.

We also have a range of grants, which can help at challenging times.

To find out more, visit **cysticfibrosis.org.uk/financialsupport** or contact our Helpline.

Online community

On our forum people affected by CF can share experiences, connect, and support each other in a safe, private space.

It features a wide range of topics, which makes it easier to find the discussions you're interested in, while avoiding those you'd rather not be a part of.

Visit **forum.cysticfibrosis.org.uk** to join the conversation.

How can we connect with other families?

Cystic fibrosis can be an isolating condition for families. The risk of cross-infection means parents of children with CF cannot meet up as easily as they might like, and often miss out on the chance to talk to someone who knows how they feel.

When you feel the time is right, connecting with other parents and families who have a child with cystic fibrosis and share the same worries as you can be invaluable.

What's next?

You might like to:

- speak to a trained volunteer who also has a child with CF through our CF Connect programme
- read about other people's experiences in our magazine, **CF Life**
- connect with people on our social channels
- visit our website at **cysticfibrosis.org.uk/parentevents** to find out about the events and support we offer for parents/carers and children
- chat to other families by joining our online community **forum.cysticfibrosis.org.uk**
- ask your CF team if they can connect you with other families affected by CF.

> **"I just needed to talk to someone who understood what I was feeling because they'd been there..."**
>
> Parent of a child with CF

No-one understands what you're going through like people who've been through it too

CF Connect is a peer support service from Cystic Fibrosis Trust, for parents, carers and families of children and young people with CF.

CF Connect volunteers offer a listening ear and the chance to share experiences in an understanding and supportive way. Those who have used the service have found it really helpful to speak to someone who understands what it's like to be a parent or someone who cares for a child with CF.

You can access our **CF Connect** service by contacting our Helpline. Give us a call or send us an email and our team will put you in touch with one of our trained parent volunteers.

Whether you're a parent, grandparent, uncle, aunt, or even a friend of the family, our volunteers are there to listen and help.

Helpline **0300 373 1000**
helpline@cysticfibrosis.org.uk

Cystic Fibrosis Trust

Trusted Information Creator
Patient Information Forum

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

We won't stop until everyone can live without the limits of cystic fibrosis.

You can also ask for this resource in large print or as a text file.

Email **infoteam@cysticfibrosis.org.uk**

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cysticfibrosis.org.uk

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