



Cystic Fibrosis here for parents



Parent information pack
Cystic Fibrosis Trust

Introduction

Cystic fibrosis (CF) affects every family differently. No two children are the same. There are big differences in the extent to which CF can cause symptoms and every child's unique personality will affect how they react to life and cystic fibrosis. Many parents have told us that they felt extremely isolated at diagnosis. They and the Cystic Fibrosis Trust want you to know that you are not alone. This booklet will give you information about the support that is there for you should you need it.

Everyone copes differently, depending on their circumstances and their own approaches to dealing with new challenges. There is no 'standard' experience of CF and this booklet cannot give you the answers to everything you might want to know. Instead, it provides a brief overview and some information about how CF might impact on your daily life.

Everyone has different information needs. Even within the same family one parent might want to know everything while the other prefers to operate on a 'need to know' basis. For this reason, **there is more in-depth information about CF at the back of this booklet should you wish to read it.** There is also signposting to even more detailed information and to useful sources of support. This booklet offers you a voice from other parents who have a child or children with cystic fibrosis.

They share their stories with you in this booklet in the hope that this might help you adapt to your child's diagnosis. Their stories highlight how babies and children with CF can enjoy their childhood; going to school, playing with friends, going on holidays and taking part in sports. These parents, and we at the Trust, are optimistic about their children's future. Through advances in care and research, we are striving to bring about the day when lives are not limited by cystic fibrosis.

Mums, dads and other family members affected by CF have helped enormously in guiding and shaping this information pack. They have generously shared their time, personal stories and experiences and we are extremely grateful to them.

We hope you find it useful.

View our film for new parents by visiting <http://cysticfibrosis.org.uk/newdiagnosis>



Cystic Fibrosis why we're here

Dear parent,

Congratulations on the arrival of your new baby.

We understand that this must be a time of mixed feelings for you. If you are anything like we were, it's a rollercoaster of emotions.

When our little girl Ruby was diagnosed at three weeks old, we were shattered. It was completely unexpected; we had no idea that anything was wrong. We desperately wanted to reclaim the happiness we'd had during those lovely days before diagnosis.

As a dad, I really struggled with the loss of control and for the first time in my life felt that I could not change the situation. Neither my wife nor I wanted to speak to people affected by CF or to the Cystic Fibrosis Trust, because we were frightened about what we would hear. We were afraid that they would confirm our greatest fears. So for a while we really immersed ourselves in research and medical information, exploring developments in genetic and drug therapies. We were looking for a solution and for hope. This was our way of coping and you will find your way. **There is no right or wrong.**

Your family is unique and your experiences will also be unique. Cystic fibrosis affects everyone differently and we all find our own coping strategies. However, you may find that some of the feelings and experiences in this booklet are similar to your own and this might help you to see that you are not alone. All the photographs in this booklet are of real families affected by CF, including my family, and we wanted to share them with you.

"There is no right or wrong.
Your family is unique and your
experiences will also be unique."

Roy and Lucinda, parents to Ruby age three



We are further into our journey now, Ruby is three and we have a new addition to our family too. I would say that 99% of our life is 'normal', whatever that really means with two young children! My advice to myself at that hard time of diagnosis would be – "it will never be as bad as you think right now".

There are difficult times, and we still sometimes feel sad and anxious. However, we are very positive about Ruby's future and enjoying our family life together.

Wishing you all the best,
Roy, Lucinda, Ruby and Monty



"I would say that 99% of
our life is normal, whatever
that really means with
two young children."

Roy and Lucinda, parents to Ruby age three





Chloe age nine months
and dad Stuart

You and your baby



"We were extremely frightened when Grace was diagnosed. We worried a lot when she was little, especially about her diet and gaining weight."

Jen and Geoff, parents to Grace age eleven



You

It might seem odd to start with **you**, but **your** health is also important. Looking after yourself not only helps you to cope with this new situation but also to enjoy the new life that you have brought into this world. You might find this advice, from other parents of children with CF, helpful.

"We would encourage you to reach out for support and try not to isolate yourself. If you had planned to join a particular baby group, go ahead and do that – speak to the baby group organiser if you have concerns. If people offer to help – take them up on it! Having a new baby, even without CF, can be exhausting and you have even more to cope with – so lean on your support networks and don't be afraid to ask for help."

Advice from a group of mums of children with cystic fibrosis

"A CF diagnosis can be completely overwhelming, but you can adjust to this new situation slowly, you don't have to know everything today. So don't put too much pressure on yourself to plan for every possibility – instead try to think about what you need to know for the here and now."

Mums attending a focus group to talk about new diagnosis

Whatever you feel at the moment, it is likely that others have felt that too. Parents have told us that they felt better about the diagnosis as time goes on – they develop more confidence in the treatments, more knowledge about the condition, more experience of high quality family life and more hope for the future. Some parents have felt frustrated because they didn't enjoy their new parenthood more.

"At first I think I did avoid doing some of the things I'd planned to do when Joseph was born because I was anxious about his CF, and I did feel isolated. But by the time he was about six months old, I felt more confident and I started going to a swimming class with him, and then a music group. I then met other mums and was able to enjoy Joseph and make the most of the baby stage."

Mandy, mum to Joseph age eleven

"I feel sad that I missed out on Beth's first year because I was so consumed with Beth's health. I wish I had enjoyed her more."

Cheryl, mum to Beth age two

Parents have told us that they have many different feelings about diagnosis. Some adapt quickly and others struggle to come to terms with their new reality.



Your baby's diagnosis

Children in the UK are routinely screened for CF using the Guthrie (or heel prick) test. As a result **most children are diagnosed shortly after birth**. For many parents this comes completely out of the blue. Others may have realised there was a problem either before birth through scans during pregnancy or shortly afterwards. The way you find out about cystic fibrosis can have a big impact on how you feel about the diagnosis.

“When I went for my 20-week scan I was told that my baby had an echogenic bowel; I was told this could be a number of different things. After having a blood test, a few weeks later it was confirmed that I carried a CF gene. I was devastated. Another few weeks later my husband’s blood test was also confirmed. Leading up to the birth I was terrified of how our lives would change and whether I would bond with my baby. But when she was put into my arms, all my fears disappeared as she was so beautiful. She was quickly whisked away as she had meconium ileus and they needed to get her into a special care unit. She was taken separately from me in an ambulance an hour and a half away to St Michael’s in Bristol. I followed in a hospital car. This was very distressing for me as I just wanted to be with her. Two weeks later I was able to take my beautiful baby girl home. She is a complete joy and has truly enriched our lives.”

Amanda, mum to Hannah age seven

“Sammy appeared healthy for the first week or so but then began to lose weight. I was breastfeeding constantly. Sammy cried a lot and wouldn’t settle or sleep well. At seven weeks, the health visitor phoned me to say a specialist nurse would be visiting to discuss the results of Sammy’s Guthrie test; she asked if I had anyone at home with me. As I waited for the specialist nurse to arrive, I didn’t know what to think, and feared the worst. I think because I had feared the worst, I had a moment of relief when she told me it was cystic fibrosis.”

Juliette, mum to Sammy age twenty months

“Chloe was diagnosed at 16 days old through the heel prick test. I had suspected something was wrong because she was feeding and having bowel movements constantly. When we got the diagnosis, I felt distraught. The doctors and nurses at the hospital were really encouraging, they answered all my questions. They were a really good support.”

Michelle, mum to Chloe age nine months



Chloe age nine months

“Although the diagnosis was a bombshell, I actually felt relief because I felt it could have been so much worse. My husband did not feel relief; he was devastated. We both blamed ourselves; we didn’t know we were carriers.”

Leona, mum to Irvine age two

“Dylan wasn’t diagnosed until he was five months old because he had quite unusual symptoms. My husband and I knew there was something medically wrong with Dylan, he was quite poorly, but doctors thought it was a neurological condition. We had really good support from the healthcare team but we just wanted to have confirmation of what was wrong so we could move on and deal with it. When we did get the CF diagnosis we were glad that we understood what was wrong and that Dylan was now being cared for by the correct team.”

Vicky, mum to Dylan age twelve

Some parents describe their initial feelings around the time of diagnosis as a type of grief; they may feel a loss and sadness for the family life they had imagined.

“My little boy, Noah, was diagnosed through the heel prick test at 17 days old. He is my first child so I didn’t know what to expect in those early days. When he was diagnosed, I was shocked and definitely experienced a grieving process. I grieved for the healthy baby I had expected and for the loss of my dream. When Noah started his treatment, he began to thrive.”

Jackie, mum to Noah age 18 months

“I knew there was something wrong because Caspar was not gaining weight, but I felt that I was being blamed because there was something wrong with my breastfeeding. It took a long time to get the conclusive result and I was shocked. I was not aware of any CF in our families. I felt the first year of Caspar’s life was really difficult both coming to terms with the diagnosis and learning about the medications and physiotherapy. However, with the support of the CF team I picked things up quickly, as did Caspar, and it became second nature in no time. I also sometimes felt that there was pressure to discuss his condition when I was with other mums. I soon realised that it’s not important for everyone to know.”

Adele, mum to Caspar age seven

“I grieved for the healthy baby I had expected and for the loss of my dream. When Noah started his treatment, he began to thrive.”

Jackie, mum to Noah age 18 months



What now?



"It took a long time to get to grips with the treatment and it still takes hard work and commitment but it does get easier. Having a routine really helps."

Juliette, mum to Sammy
age 20 months



What now?

Families experience and cope with CF in different ways. **The journey is not predictable** and some children will be very well whereas others may be more poorly. There are differences in personalities too with some children, regardless of CF, being less compliant than others!

Cystic fibrosis means your child may have to take a number of medicines and do a lot of physiotherapy to help them be 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.

"I remember when he was first diagnosed and we were sent home with a giant bag of medication – it felt totally overwhelming. Within weeks of starting the medication, Lewis started to thrive. He's now nine and a half and a normal happy boy – he loves football and he hasn't ever really been ill. We talk to him about physiotherapy just being like brushing his teeth – it's just something he has to do to look after his body."

Katie, mum to Lewis age nine

"It's not that big a deal, you can do lots of normal stuff, I love to dance, cycle, compete in athletics and ride rollercoasters. I don't always want to do my medicine and physio, but I just get on with it... Really you shouldn't worry because my life is amazing."

George, age ten

"I love to dance, cycle, compete in athletics and ride rollercoasters. I don't always want to do my medicine and physio, but I just get on with it."

George, age ten



Diet



Cystic fibrosis can cause sticky mucus to build up and block the pancreas. The pancreas, makes the digestive juices (enzymes) which are needed to help breakdown food and absorb nutrients. If the digestive juices can't get out of the pancreas, babies struggle to gain weight. They can be difficult to settle because they always feel hungry. Enzymes (often called Creon) are given to babies with their feeds if they have a problem with their pancreas. Replacing the missing digestive juices to **help children with CF grow normally** is one of the most important things that can be done to help keep them healthy.

"We know that the thought of giving your baby medication can seem really overwhelming. It's tricky to get the dosages right at first and you might feel quite anxious. But it does get easier and you start to instinctively know the amount of Creon needed. You probably know this already, but mixing the granules with fruit puree is often the best way forward! It's a great idea to freeze the puree in ice cube trays so you always have a good supply and in convenient amounts. Ask your CF team about the best time for your baby to start on purees."

Advice from a groups of mums of children with cystic fibrosis

"At the beginning it seemed to take me hours to prepare everything, get the Creon organised – but now it's just routine. We get it all organised in the morning and then we get on with our day."

Sarah, mum to Rhys age three

"To start with, I found it fiddly measuring the Creon with a tiny scoop and then getting it on to the spoon with the fruit puree for Caspar. It didn't help that strangers would sometimes look on! So I was self-conscious about giving him his Creon but that's all second nature now.

Adele, mum to Caspar age seven

Your dietitian will be able to help you when the time comes to move onto solids. As with all children, you may find that your little one has particular likes and dislikes and weaning may be a process of trial and error! With help from your dietitian, you will find your own routine and menus to suit your family.

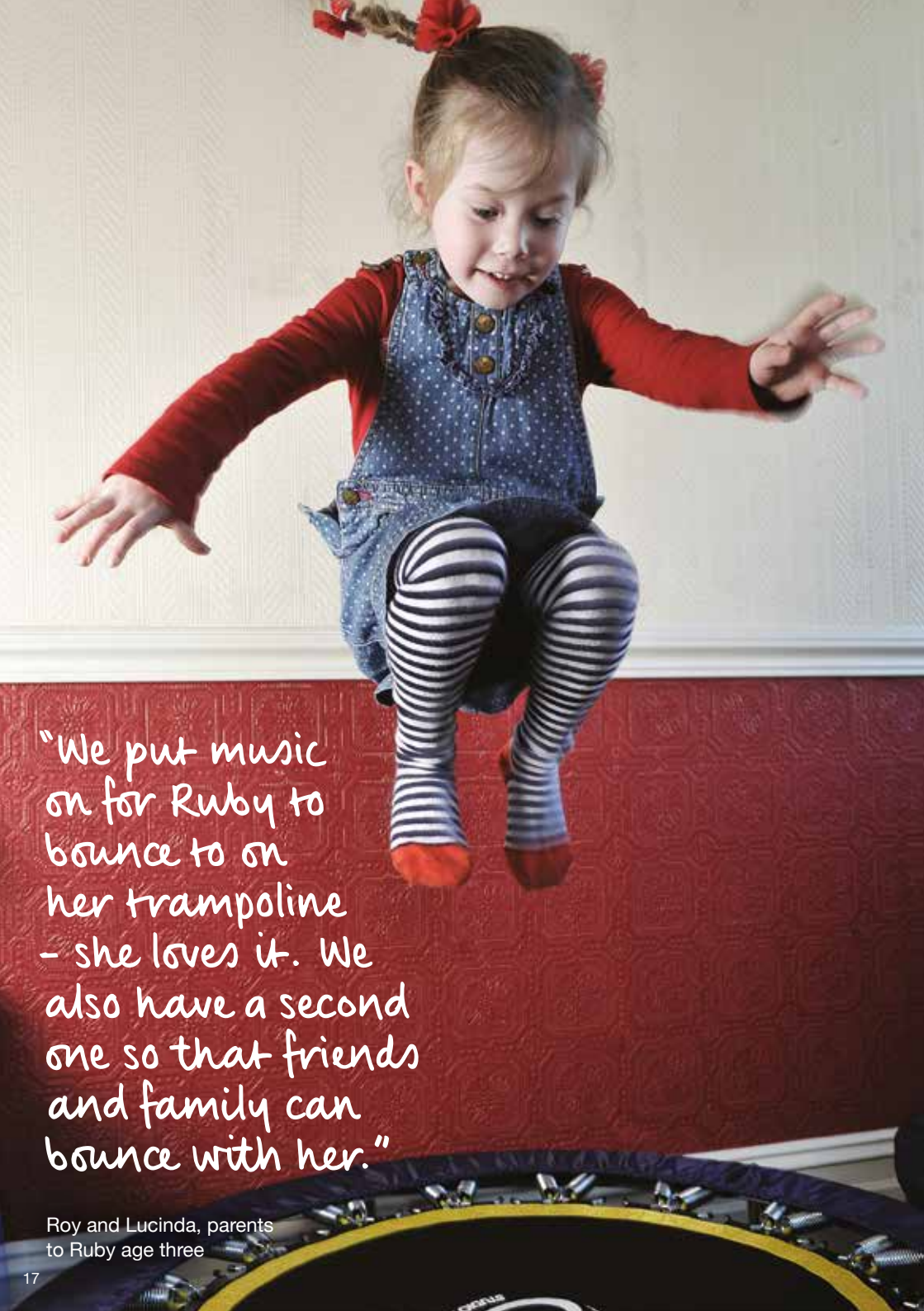
"We are very committed to making sure that Ruby gets a balanced diet that also gives her the energy she needs to compensate for the cystic fibrosis. So she'll have chilli for example with lots of vegetables but I'll also add in sour cream and cheese to increase the fat and she loves that. She enjoys her puddings so we give her custard but also lots of fruit."

Roy and Lucinda, parents to Ruby age three



"It was actually a huge relief when Sammy started on Creon. He very quickly began to absorb his milk better and so felt less hungry."

Juliette, mum to Sammy age 20 months



"We put music on for Ruby to bounce to on her trampoline - she loves it. We also have a second one so that friends and family can bounce with her."

Roy and Lucinda, parents to Ruby age three

Physiotherapy



Cystic fibrosis causes thick, sticky mucus to build up in the airways. This can cause infection and damage to the lungs. To keep the airways clear of this mucus, physiotherapy exercises will be recommended to you by a specialist physiotherapist in the CF team. Every child will have an **individualised physiotherapy programme**. Parents have told us that it's helpful in the long run to try and make physiotherapy fun, even from an early age. Use your imagination when doing physiotherapy to make it fun by making it into a game. Making use of toys like trampolines can be fantastic – children of all ages love to bounce.

"I try to make physio a fun time for Irvine. I jump with him, and pretend to be a horse! He enjoys that. Irvine is two so he is starting to get heavier and so I use cartoons to distract him. He's very accepting of the physiotherapy though."

Leona, mum to Irvine age two

"Noah has never liked the physiotherapy treatments. I have struggled to cope with this sometimes, and as he's only 18 months old I can't reason with him. I did find in the past that doing physiotherapy in front of the mirror worked well for Noah for a little while. Now that he's a bit bigger and heavier. I tend to use the television to distract him."

Jackie, mum to Noah age eighteen months

"Ethan was so tiny and fragile that doing physiotherapy with him really worried me. I was really well supported by the physiotherapists at the CF centre but it still took me a few months to get used to doing his treatments. Ethan is eight now and incorporates his treatments into his daily routine really well."

Catherine, mum to Ethan age eight

"Beth protested against physiotherapy as a baby. However, as she got older she would wake up and then cry, but we persevered. Beth is two now and is very grown up and accepting of her treatments. She now wants to hold the PEP mask herself (with a little help from me!)"

Cheryl, mum to Beth age two



Physical activity



Although it's early days for you and your new family, you should try to build physical activity into your life as soon as possible. Being physically active is **really good for your child's lungs**. Children are more likely to be physically active if their parents are. Children with CF should be able to participate in most activities as they grow up.

"I love football and I play it everyday and my CF doesn't stop me. I can even watch 'Match of the Day' while I have my physio."

Lewis, age 9



"Dylan is very sporty and loves football in particular – he's really good at it and plays in the school team and for the District. Since he was little, we've always strongly encouraged physical activity – we think it's really important for his health and great for the rest of the family too! Dylan fits CF into his life, it doesn't stop him. He does his physio exercises on the way to football in the back of the car. He's really good with his treatments and he's motivated to do them so he can play his best at football. We found that because Dylan has CF, he was entitled to reductions at our local sports and leisure facilities – it's worth checking out."

Vicky, mum to Dylan age twelve



Chloe age nine months with dad Stuart and mum Michelle



Grace age eleven

Healthy lungs

It is natural for all parents to want to protect their baby and this may be even more so for parents of a baby with cystic fibrosis. There are some bugs (such as bacteria, fungi and viruses) that people with CF can be more vulnerable to and these can thrive in certain places such as stables, very damp environments and in mud. There are also some bugs that people with CF may carry in their lungs which could be harmful to other people with cystic fibrosis. This is why people with CF are strongly recommended not to mix. This can be isolating for new parents.

Some parents have said to us that, in the early days, they felt anxious about their little ones picking up infections. However they also said that as time passed they sometimes reassessed what 'risks' were worth taking to enable them all to have a normal family life. **For most families, life is pretty much normal**, with some small compromises.

"Caspar is my second child. When he was diagnosed we made a few changes to our home, but he is able to do anything that we want to do as a family. Although I don't encourage him to jump in muddy puddles and I wouldn't allow him to muck out horses. He has done seed planting, with lots of hand-washing, and he plays rugby now."

Adele, mum to Caspar age seven

"I have a list in my head of the things I'm happy for him to do and the things I don't want him doing because of his cystic fibrosis. Over the years I've been told about the risks of picking up bugs by the CF team and from other parents, and what's OK and what isn't. It can be worrying, but you learn to weigh up the risks and decide what matters to you – it's probably different for every family."

Katie, mum to Lewis age nine

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Katie, mum to Lewis age nine

Other siblings

If your new baby has an older sibling, you may find that this **helps to normalise life**. It is likely that your older child will still expect the same routine and attention. It can, of course, be hard for them to deal with the arrival of a new sibling along with the additional attention that CF may bring.

"I do think it must be tricky for Arthur, who doesn't have CF, and we try to involve him wherever possible - he does exercises in the morning when we're doing the girls' physiotherapy or if they are doing bubble pep, he has his own apparatus too."

Kate, mum to Arthur, age nine, Poppy, age seven, and Lily age four

"Poppy was diagnosed with CF through the heel prick test. Her big brother Arthur, who doesn't have CF, was only two years old at the time. Luckily, we didn't have any big issues of jealousy from Arthur. I guess he may have thought that the medicine and physio were just what any baby needed, he was still young and didn't know any different. We tried to make sure he was involved with looking after Poppy whenever he wanted and he always came along for hospital visits so he felt included."

Kate, mum to Arthur age nine, Poppy age seven and Lily age four



Ruby age three and new sibling Monty



Sammy age twenty months and brother Joseph



Ruby age three and dad Roy

Advice from other parents!

Enjoy your baby



It's hard, but try not to spoil or over protect your child...

...try to let them have the childhood you'd imagined

Ask for help, advice and support



Persevere! - things get easier!



Establish a good relationship with your pharmacist



Be very careful with the internet - there's a lot of inaccurate information

Stick to recommended websites



www.cysticfibrosis.org.uk

Don't put your life on hold



Don't isolate yourself





Sammy age twenty months
and mum Juliette

Your future



"There are difficult times, and we still sometimes feel sad and anxious. However, we are very positive about Ruby's future and enjoying our family life together."

Roy and Lucinda, parents to Ruby age three

Your future

We can't predict the future but in recent years there have been **fantastic advances in research** resulting in new and better treatments. We don't know what the life expectancy is for a baby born now, but there is every reason to be very hopeful about the future. There are challenges and compromises with CF and it will always be part of your family, but as the stories for these parents have shown, there is every reason to be positive.

"At first I just fixated on the idea that George might have a shortened life expectancy. After the diagnosis we definitely went through a period of grief – there is a feeling of loss, and we didn't dare to dream too far into the future. We did feel sad about it when he was younger but it's reassuring to know that there's always research happening and it will make a difference, and you feel you can have an impact by making sure all the necessary treatments and physiotherapy are done. George is 10 now, and a normal happy boy who is excited about his future. George's diagnosis has taught us to enjoy life and make the most of everything. We cycled 100 miles last year to raise money for the Cystic Fibrosis Trust: George not only did it with us, but was often at the front rallying us on; we're so proud of him."

Kirsty, mum to George age ten

"We were extremely frightened when Grace was diagnosed. We worried a lot when she was little, especially about her diet and gaining weight. We obviously prioritised Grace's health over everything else and that may cause some problems in future. It's hard because we ask a lot of her in terms of doing her treatments so we feel we don't want to push her on everything. I think I'd say that although we will always have a 'cloud' of worry and anxiety, it has certainly diminished. Grace is getting ready to go to high school and does all the things girls of her age might enjoy including excelling at her trampolining club."

Jen and Geoff, parents to Grace age eleven

"As a family, we've built CF into our lives."

Vicky, mum to Dylan age twelve



"I don't make a big deal of having cystic fibrosis. My close friends know about it, and they are very supportive, but I prefer to just get on and deal with it."

Isobel, age fifteen

The parents we've spoken to are keen to let you know that **your future may be more 'normal' than you might think** just now.

"Aimee has always been very well and has never required a hospital admission for her cystic fibrosis. We don't need to make many compromises for CF and I don't feel that the CF affects the way I treat Aimee. I know that not everybody has this experience."

Allison, mum to Aimee age seven

Parents have told us that there are difficult times with CF but that for the most part their child is able to do the same things as other children; holidays, parties, school, sports, hobbies and friendships.

"We took Beth to Mexico for a holiday last year – she loved it."

Cheryl, mum to Beth age two



Ruby age three



"I think I'd say that although we will always have a 'cloud' of worry and anxiety, it has certainly diminished. Grace is getting ready to go to high school and does all the things girls of her age might enjoy."

Jen and Geoff, parents to Grace age eleven



And finally...

My name is John, my wife is Ellen and the cute little chap in the photo is our son, Joshua who is six months old. I love being a dad. Joshua and I enjoy 'Daddy days' every Friday when I take the day off work and we have great fun together. I work for Microsoft Research, as principal researcher in Artificial Intelligence. It's a role that's ideal for my background having achieved a degree in Engineering at Cambridge and then a PhD at MIT in Boston. My job has also given me more opportunities to travel, taking me to China, USA and Australia. Ellen and I have enjoyed travelling in Africa too and our home is full of photographs and art documenting our adventures. I enjoy playing the odd game of tennis, swimming and also cycle to and from work each day. And by the way, I also have cystic fibrosis.

Having CF hasn't stopped me achieving my ambitions or pursuing my dreams and it doesn't define me. I manage the CF around my life, working together with my amazing CF team. There are definitely compromises and CF can be difficult at times. When Ellen and I got married in 2013, I was having IV antibiotics and didn't feel 100% but it was still the best day of my life. Of course I would rather not have been on antibiotics that day, but our wedding was so much bigger than cystic fibrosis. I'd never dared think about becoming a dad, I didn't think that could happen for me. But developments in fertility treatments meant that we were able to welcome Joshua into the world in 2014.

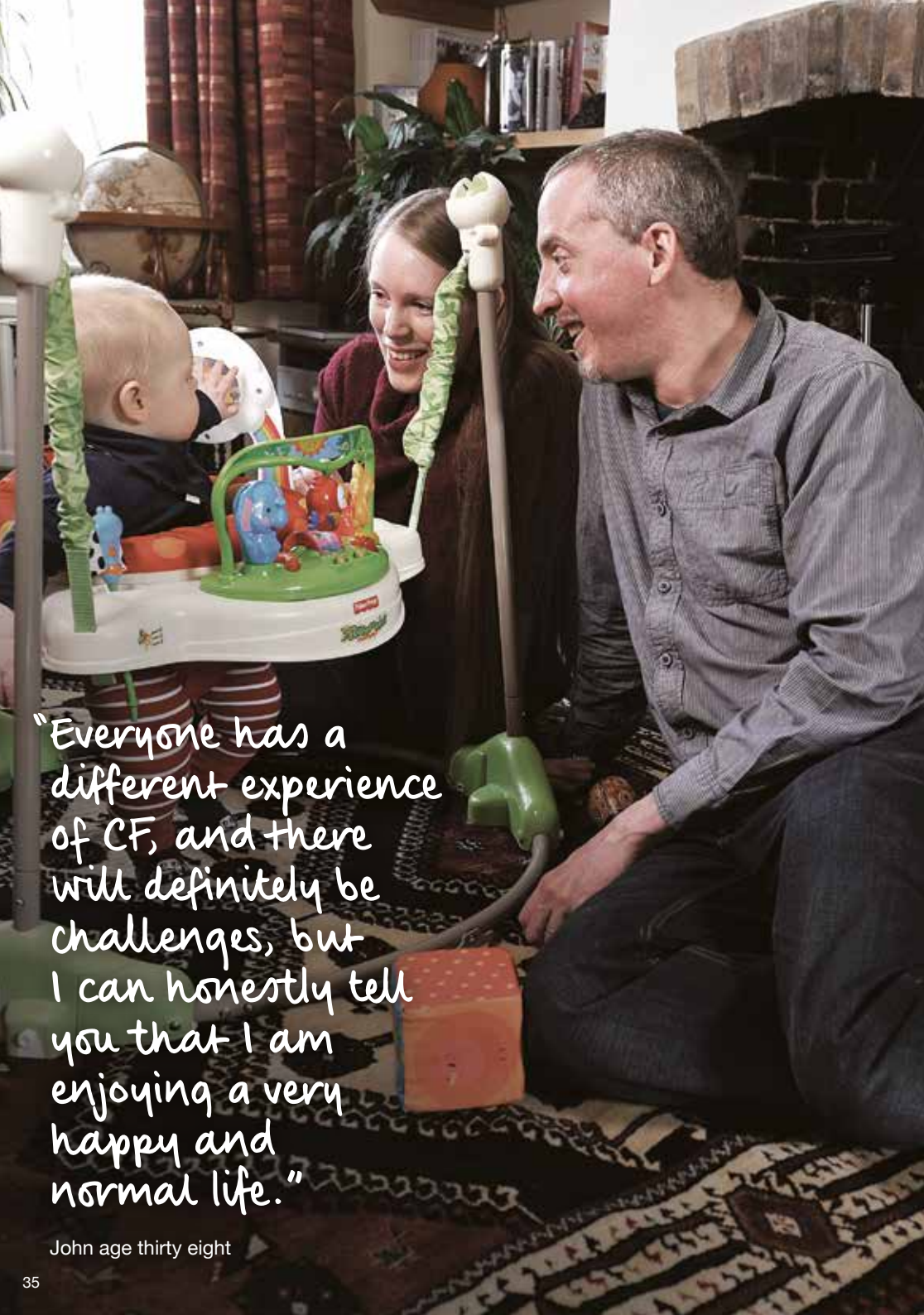
Joshua does not have CF, so I don't know what it's like to be a parent of a child with CF. When I was diagnosed, my parents were very concerned and I think they may have spoiled me as a result. But that was nearly 40 years ago and things were very different then. There was no heel prick test so CF was often picked up much later; there was no Creon and there was nothing like the treatments and understanding of the disease that doctors and scientists have now. Research and development has come on in leaps and bounds in the past couple of decades – it's amazing. My advice to you is to try not to worry too much – easier said than done I'm sure, but there is a huge amount of research pushing every day to improve treatment of CF and I feel very hopeful about the future.

Everyone has a different experience of CF, and there will definitely be challenges, but I can honestly tell you that I am enjoying a very happy and normal life.

John age thirty eight

"My advice to you is to try not to worry too much - easier said than done I'm sure, but there is a huge amount of research pushing every day to improve treatment of CF and I feel very hopeful about the future."

John age thirty eight



More about CF...

"Everyone has a different experience of CF, and there will definitely be challenges, but I can honestly tell you that I am enjoying a very happy and normal life."

John age thirty eight





Grace age eleven

More about CF...

This section provides a little more information about cystic fibrosis and the treatments available. More detailed information is available on the Cystic Fibrosis Trust website cysticfibrosis.org.uk or by contacting our helpline on 0300 373 1000 or helpline@cysticfibrosis.org.uk

CF and genetics

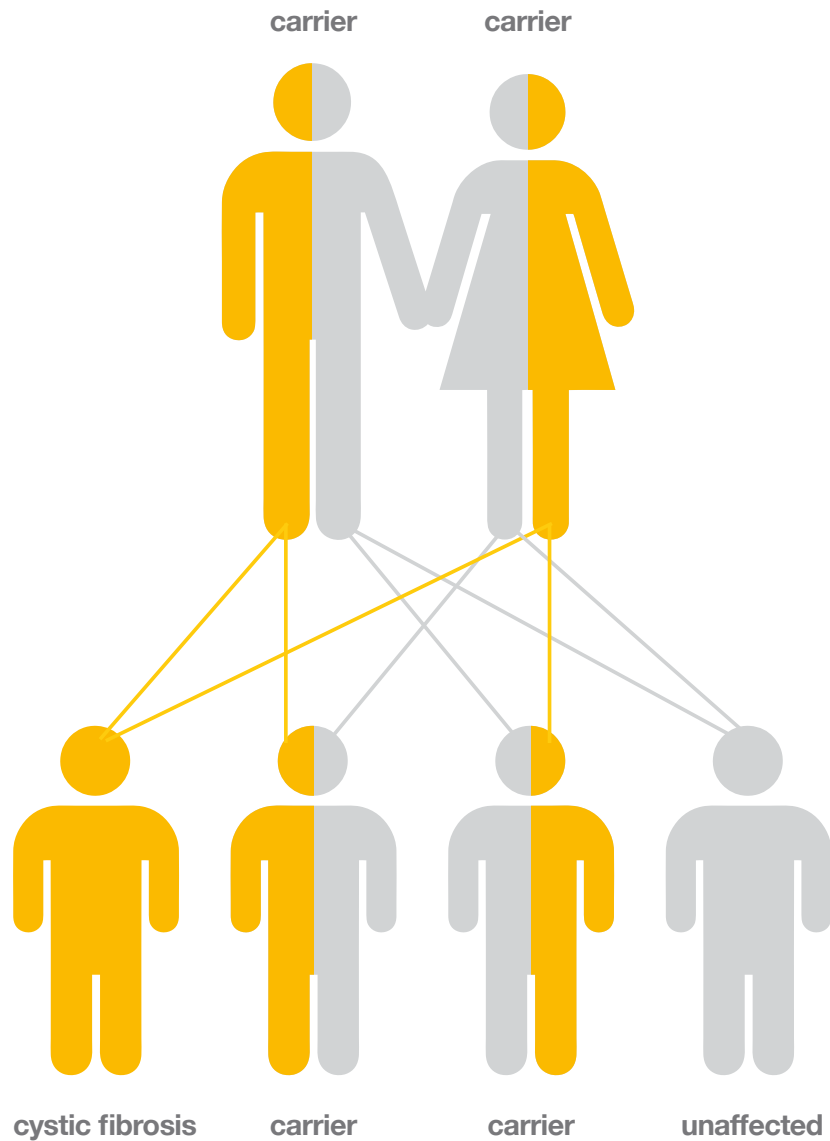
Genes are what make us 'us'; they direct all our cells to carry out all the jobs needed to make our bodies work. They control how we look; for example our hair, skin and eye colour, build and height. In CF, the gene that controls the movement of salt and water in and out of the body's cells has a fault (also called a mutation). This fault causes the body to produce thick sticky mucus that affects the lungs and digestive system.

Cystic fibrosis is genetic condition. A baby can only be born with CF if both parents are carriers of the cystic fibrosis gene. **Most people will not know they are carriers.** Even if both parents carry the CF gene there is still only a one in four chance that their baby will have cystic fibrosis, as shown on the diagram over the page. The risks are the same for each pregnancy.

Not all children are affected in the same way or to exactly the same degree; some are affected more and some less. This is because the gene can be mutated in many different ways. More than 1,400 different mutations have now been identified. Different mutations respond differently to treatment, so what works for one person with CF may work less well for another. Your child's CF team should be able to tell you what two mutations have resulted in them having cystic fibrosis.



Diagram showing how CF is passed on from parent to child



John age thirty eight

How does CF affect the lungs?

We all have a small amount of liquid and mucus in our airways which help keep them healthy. In people with CF the mucus produced is very thick and sticky, which starts to clog up some of the smaller airways and leads to infection. If your baby develops a chest infection they will have to take extra antibiotics to kill off the bacteria and prevent damage to their lungs. Babies and children with CF may also be prescribed preventative antibiotics. If an infection is not controlled, the lungs can be damaged.

Chest physiotherapy is a way of clearing the excess mucus from the lungs. There are different ways that chest physiotherapy can be given. Your CF centre will teach you the best method for your baby or child. Sometimes physio can be challenging but your CF team and physiotherapist will be able to help you. **Ask the physiotherapist to watch you doing physiotherapy** from time to time, to make sure that you are still doing it as effectively as possible.



How does CF affect the digestive system?

The effect of cystic fibrosis on the pancreas and digestion varies from person to person. Without treatment, the majority of newborn babies with CF cannot digest milk and fail to gain weight. **Your baby is likely to need to take enzymes (usually called Creon)** to replace the digestive juices which are blocked inside the pancreas. These enzymes will help your baby to break down and 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.



Creon can be an important part of CF medication



Sammy age 20 months with dad Mark and brother Joseph

What does all this mean for our family?

It means that you will have to fit your baby's treatment into your daily routine and family life. However, as families in this booklet have shown, **normal family life can continue** and, in time, you may find that you don't usually have to think too much about cystic fibrosis.

Can my child do the things other children can?

Mostly.

Cystic fibrosis does not affect brain development so children with CF attend preschool and school in the usual way and can go onto further education and employment. Allowances may have to be made for absences for clinic visits or if your child has an infection and needs a break from school. Schools have guidance in place for this and should be very supportive. Your CF team can offer guidance and support for the school.

Regular exercise is an important part of care for children (and adults) with cystic fibrosis. It helps keep the lungs healthy, improves physical strength and is very good for keeping bones strong. Toddlers often like running, jumping and trampolining, all of which are very good for them. When at school, children with CF can take part in P.E. and games just like other children in their class and they'll benefit from lots of encouragement to do physical exercise out of school, such as cycling, football, swimming, tennis, etc. It is often more fun to have company when exercising, so you can plan some of these activities with the whole family.

Who will help us?



CF teams

You should already be in contact with your CF team. They will be the key providers of your baby's care. The team will include CF specialist nurses, doctors, physiotherapists, social workers, psychologists, pharmacists and dietitians. They are experts in CF and will be able to advise you on any questions or worries you have about your baby or child. It's sometimes helpful to write down questions before clinic appointments.

The Cystic Fibrosis Trust

We are here for you in a number of ways; **the helpline (0300 373 1000 or helpline@cysticfibrosis.org.uk)** is here to support you by providing advice, information or just someone to talk things through with. There is also our **CF Connect service**; matching you with a volunteer who is also a parent of a child with cystic fibrosis. They can offer a listening ear and the chance to share experiences – many parents really value the opportunity to talk to someone who can really understand how it feels to have a baby or child with cystic fibrosis. The Trust also provides a range of information online and factsheets/booklets can also be posted to you. We also have an online community, which you can access via our website. Crucially, we also raise money to fund research to beat CF for good and work to improve the care that is provided in specialist CF centres.

Local pharmacist

It is useful to **establish a good relationship with your local pharmacist**. 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.


GP

Although your baby will receive their CF care at a specialist CF centre, like all families you will have contact with your local GP. It's helpful to try and 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.

What's my baby's future like?

We believe it is positive. The developments in research in the past 20 years have been incredible. The arrival of **Kalydeco™** (you may also hear it called **ivacaftor**) has generated much excitement. It has been shown to be highly effective in treating CF in people with a particular mutation and there is a huge amount of research and drug development looking at other tailored treatments (for particular mutations) and for CF more generally.

Life expectancy has increased massively. In the 1960s children with CF often did not live beyond school age, but today the majority of people with CF have childhoods, adulthoods and, in some case, their own families. There are many published figures concerning life expectancy, particularly on the internet. It is important to know that such statistics are averages and cannot be applied to any one individual – everyone is different. These statistics are often not helpful to parents. Improvements in modern CF care give us great hope that children born today may have a near normal life expectancy. The Cystic Fibrosis Trust is committed to shaping a future where everyone with cystic fibrosis can live a life unlimited by their condition.



"When Chloe was diagnosed I didn't know where to turn for information and reassurance. But now I know where to get good information, I feel more supported."

Michelle, mum to Chloe
age nine months

I need more information

This booklet provides an overview of CF and we understand that some people might want more detail. On our website www.cysticfibrosis.org.uk you will find a wide range of factsheets which will give you more detail on cystic fibrosis. There are also pages dedicated to more detailed clinical and research information. Alternatively, you can contact us on **0300 373 1000** or helpline@cysticfibrosis.org.uk to request more information.

I need more support

The Cystic Fibrosis Trust helpline can help you with a range of issues, no matter how big or small. Our trained staff can provide a listening ear, practical advice, welfare/benefits information or direct you to other sources of support. The helpline can be contacted by calling **0300 373 1000** or helpline@cysticfibrosis.org.uk and is open **Monday to Friday from 9am-5pm**.

On the Trust's website you will also find an online CF forum where people affected by CF can share experiences and support each other. We can also put you in touch with a trained volunteer who also has a child with CF through our CF Connect service.

Cystic fibrosis can bring its own financial burden, so the Trust provides a range of grants for people with cystic fibrosis and their families that struggle to meet these costs. Please contact our helpline to ask about these grants. The Trust can also provide information and support on issues including benefits, employment and housing.

You're not alone. Support is available from the Cystic Fibrosis Trust and your specialist CF team as and when you need it.

"You're not alone."

Cystic Fibrosis Trust



Cystic Fibrosis why we connect

CF Connect is a new service from the Cystic Fibrosis Trust. We can put you in touch with a trained parent volunteer who you can talk to in confidence about having a child with cystic fibrosis. Our volunteers are all parents of children with CF, so as well as offering a listening ear, advice and support, they also understand the challenges you may be facing.

To connect with another parent through CF Connect contact our helpline on **0300 373 1000** or helpline@cysticfibrosis.org.uk

"I just needed to talk to someone who understood what I was feeling because they'd been there..."

Kirsty, mum to George age ten



We understand that 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. That's why we've set up CF Connect: a service where you can speak to a trained volunteer who also has a child with cystic fibrosis.



CF Connect volunteers can offer a listening ear and the chance to share experiences in an understanding and supportive way.

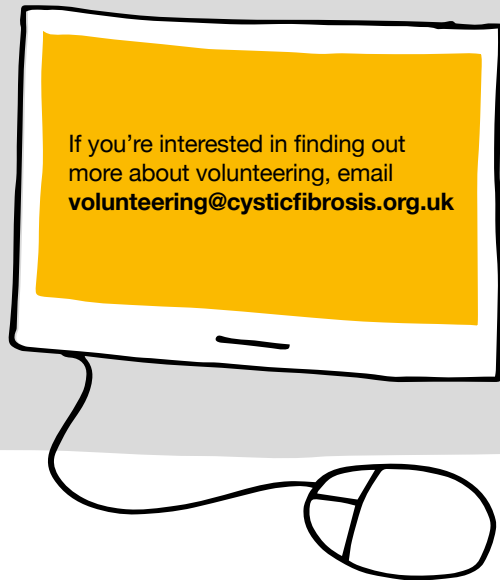
Whether your child has been recently diagnosed with CF, or whether you've got worries or questions further down the line, CF Connect can put you in touch with someone who understands.

CF Connect is run by our helpline team – please get in touch and we will put you in contact with a CF Connect volunteer by phone or email. You don't have to be a parent to use the service – you could be a grandparent, uncle, aunt, or even a friend of the family. We have volunteers across the country, who have children of different ages and are there to help.

Cystic Fibrosis Trust helpline:
0300 373 1000 or
helpline@cysticfibrosis.org.uk

Could you be a CF Connect volunteer?

We're looking for volunteers from across the cystic fibrosis community to provide this vital support service. The hours are flexible – you can give as much or as little time as you want, and we'll provide the training and support.



CF Team Contact Details

Hospital name:

Address:

Telephone number:

Email address:

CF Consultant:

CF Nurse:

CF Physiotherapist:

CF Dietitian:

Other key team members:

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cysticfibrosis.org.uk

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