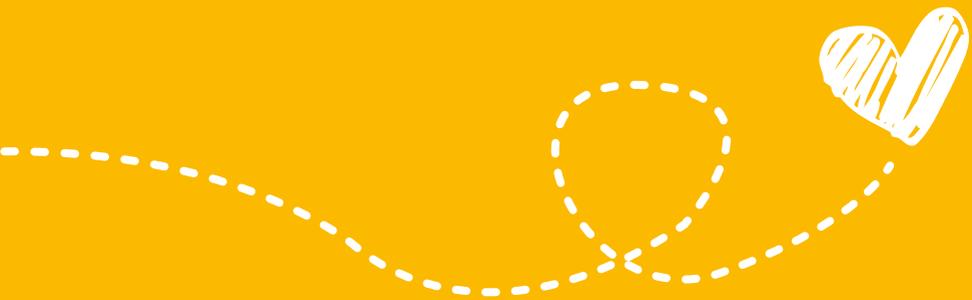


Cystic

**Fibrosis here for
friends & family**



Friends & family guide
Cystic Fibrosis Trust

Your relative or friend has given you this leaflet because their baby has been diagnosed with cystic fibrosis (CF).

What is cystic fibrosis?

Cystic fibrosis is an inherited condition caused by a faulty gene. You cannot catch cystic fibrosis, or develop it later in life. People with CF are born with it and will have it for life.

The faulty gene causes a build-up of thick sticky mucus, especially in the lungs and digestive system. This may cause a range of symptoms including frequent chest infections, shortness of breath, a prolonged cough and difficulty in gaining weight. However, CF affects different people in different ways.

Some people will have obvious symptoms while others won't. Although there is no cure for cystic fibrosis at present, research is moving very quickly and **treatments are improving all the time**. 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 cases, their own families.

There is every reason to be very hopeful about the future.

How will this affect my friend's/relative's baby?

The mucus in the baby's lungs is very thick and can block some of the smaller airways and cause infection. To keep the baby's lungs as healthy as possible this sticky mucus needs to be cleared. Regular physiotherapy sessions help to shift the mucus. Antibiotics to fight lung infection and drugs to thin the mucus may also be required.

The baby's digestive system may also be affected because sticky mucus can cause blockages in the pancreas. These blockages prevent the flow of digestive juices (enzymes) which then build up in the pancreas and cause damage.

The lack of enzymes also means that the baby will not be able to digest milk, or in future solid food, without treatment. Most babies need to take replacement enzymes (Creon) from birth and for the rest of their lives. It can take a lot of work to keep the baby well.

The new baby will love cuddles, interaction and stimulation in the same way as all new babies do. He or she is a baby like any other who will sleep, eat and cry! **As the baby grows, they will be able to participate in the majority of activities that other babies and children enjoy.**

How will this affect my friend/relative?

Parents are likely to feel very shocked about the new diagnosis and may feel a sense of loss or grief. Cystic fibrosis is not what the parents will have wanted for their child and they may experience a period of grief for the 'normal life' they had expected. This grief process can be complex and parents may feel angry and respond angrily or sharply – please try not to take this personally.

It takes a lot of work to maintain their baby's health as well as the usual demands of a newborn baby. The treatment burden can be especially great for families without good support networks.



What about me?

You may also feel shocked and sad. You may have questions; the Cystic Fibrosis Trust website (cysticfibrosistrust.org.uk) is a very useful source of up to date information. This website also contains information about genetic screening if you are worried about the implications for your family.

You can be a great source of support to your relatives/friends, especially if you understand a little about cystic fibrosis. Try to be strong, your relatives or friends have a lot to cope with and need you to support them – not the other way round!

What should I say?

Parents have told us that the support of friends and family is really important. Often, people don't know what to say and may, inadvertently, say insensitive or hurtful things.

Sometimes people are so worried about what to say that they say nothing at all, which can also be hurtful.

The baby is a new life to be celebrated so whilst there can be difficulties, the normal responses to a new baby are appreciated:

He's a lovely baby

She's a beautiful baby

Can I have a cuddle?

She's got beautiful eyes

Congratulations!

You can support your friends/relatives by acknowledging their sadness and saying things like:

I'm sorry this has happened. How can I help you?

I know I can't make it better, I wish I could.

I can't imagine what this is like for you. I'm here if you'd like to talk.

Please don't undermine the condition by saying:

She looks normal

He looks fine to me

He looks really healthy

At least it's not...

You wouldn't think anything was wrong

It could be worse

Some parents have also told us that comments based on religious belief aren't helpful, for example:

God wouldn't give you what you can't cope with

God gave her to you because he knows you can cope with it

What can I do?

Be practical

Parents have told us that practical help is appreciated, for example help with cooking, the school run, care of siblings, picking up a prescription or shopping. Parents often feel unable to have a break because babysitters are concerned about the treatment demands. **Being able to care for the baby, even for a short time, could be incredibly supportive to the parents.**

Be informed

Learning about CF is also a great way of showing your support. Understanding what is happening for the family will help you to support them. If you are well-informed, parents might appreciate your help in telling other people about the new diagnosis. The internet has many benefits, however it is also full of false information and inaccurate advice.

Be there

Listening and understanding will help you to support your friend or relative emotionally. There is no 'right' way to feel and allowing your friend or relative to express all emotions (anger, fear, sadness, worry and happiness) may help them at this difficult time.

It might be helpful to offer to visit while the baby is receiving their physiotherapy treatment or medications to help you become familiar with the care the baby needs. However, please don't visit if you have a cold or a chest infection and please understand if the parents ask you to wash your hands before cuddling their baby.

Please ensure that you only consult expert sites, including the Cystic Fibrosis Trust website. Parents have told us that when friends or relatives search the internet for cures and advice it can make them feel as if their own knowledge is being undermined and that they are not being listened to.

Parents will worry about their baby's future, not just the here and now, so **your continued support and understanding will be appreciated.**

More information



For more information or support please contact the Cystic Fibrosis Trust Helpline on **0300 373 1000** or look at the website **cysticfibrosis.org.uk**

cysticfibrosis.org.uk

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