

Cystic fibrosis (CF) carrier: description in brief

When your baby was about a week old, your midwife took some blood from your baby's heel (newborn blood spot screening). The blood was tested for some rare conditions, including cystic fibrosis (CF). This test can also identify babies who are carriers of the CF gene.

Your baby's screening result shows they are a carrier of the CF gene. As a carrier, your baby does not need treatment. More than 2 million healthy people in the UK (about 1 in 25) are carriers of the CF gene. This information will help you understand what your baby's screening result means.

Public Health England (PHE) created this information on behalf of the NHS. In this information, the word 'we' refers to the NHS service that provides screening.

Carrying the CF gene

Our genes allow us to inherit things such as eye colour and blood group. We all have 2 copies of each gene in our body. We inherit one from our mother and one from our father.

If a baby inherits 2 copies of the CF gene, they will have CF. If a baby inherits only one copy, they will not have CF but will be a carrier of the CF gene.

How being a carrier affects your baby

As a carrier of one copy of the CF gene, your baby does not need any treatment. Parents who are carriers do not need any treatment either.

Carriers can pass on the CF gene to their children, so it is important to tell your child later in life that they are a carrier of the CF gene.

Risk of developing CF

Your baby's screening test shows they have one copy of the CF gene. However, screening does not identify rarer types of the CF gene. Very occasionally, a child who is thought to be a carrier is diagnosed with CF later in life. If you are worried about your baby's health, please speak to your GP or health visitor. Tell them your baby is a carrier of the CF gene and that you are worried they might have CF.

Future children

It is possible that both you and your partner are carriers of the CF gene (about 1 in 25 people in the UK are carriers). When both parents are carriers, all future children have a

1 in 4 chance of developing CF. You and your partner can find out if you are both carriers. Your GP can refer you for this testing.

Information, advice and support

Other sources of information and support include:

- the NHS website, for more information about newborn blood spot screening, at <https://www.nhs.uk/conditions/pregnancy-and-baby/newborn-blood-spot-test/>
- the NHS website, for more information about CF, at <https://www.nhs.uk/conditions/cystic-fibrosis/>
- the Cystic Fibrosis Trust website, for more information about CF and what it means to be a carrier, at <https://www.cysticfibrosis.org.uk/>

More information

The NHS Screening Programmes use personal information from your NHS records to invite you for screening at the right time. Public Health England also uses your information to ensure you receive high quality care and to improve the screening programmes. Find out more about how your information is used and protected, and your options at www.gov.uk/phe/screening-data.

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