



# Newborn bloodspot screening programme

## Your baby's screening result

### Cystic fibrosis (CF) is suspected

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The result of your baby's 'heel prick' screening blood test suggests they might have cystic fibrosis (CF). This result will need to be confirmed by further tests.

By identifying CF early, babies and their families can be offered treatment and support as soon as possible.

This leaflet gives some information about CF and explains what happens next.

#### What is CF?

CF is an inherited condition, affecting mainly the lungs and digestion. A baby with CF has inherited two altered genes, one from each parent, which together cause the condition.

Babies with CF can have chest infections and difficulties digesting their food and putting on weight.

CF is a lifelong condition and all families receive regular support from a team experienced in caring for babies and children with CF.

## What happens next?

You will be given a hospital appointment for your baby to have a further test, called the sweat test, and see a team that cares for children with CF. You will have the opportunity and time to ask any questions.

The sweat test measures the amount of salt in sweat, which is increased in people with CF. A small amount of sweat is collected from the skin on your baby's arm or leg. This is not painful.

You will be given the sweat test results later the same day. Sometimes the test needs to be repeated if not enough sweat is collected.

## Treatment

If CF is confirmed, the CF team will explain what help your baby might need and what you can do to keep them well. The team includes a doctor, specialist nurse, physiotherapist and dietitian. Treatment is improving all the time, helping people with CF live longer and healthier lives.

If the sweat test is normal your child is very unlikely to have CF and the CF Team will discuss this with you.

## Support for your family

We understand this screening result is unexpected and unsettling for you and your family. You may feel a sense of shock, disbelief or anger. These are quite normal reactions experienced by many families in this situation.

You can discuss any concerns with the CF team at your hospital appointment. Everything will be done to support your family and make sure you know the test results quickly.

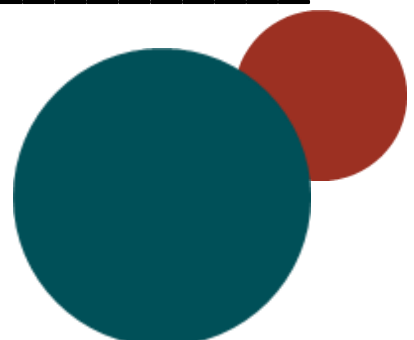
If your baby has CF, please remember that the condition has been identified very early because of newborn bloodspot screening and that this will help to give your baby the best possible start in life.

## More information and support

- Information and support is also available from the Cystic Fibrosis Trust charity that aims to improve the lives of people with CF and their families:  
[www.cysticfibrosis.org.uk](http://www.cysticfibrosis.org.uk)
- Newborn Bloodspot Screening Wales:  
[phw.nhs.wales/newborn-bloodspot-screening](http://phw.nhs.wales/newborn-bloodspot-screening)

## Notes

You can write down any notes here from discussions with your health professionals.

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins or other markings on the paper.

## Using your information

For us to contact you as part of the programme, we will need to handle some of your and your baby's personal information. If you need more information about this, you can:

- visit the website: [phw.nhs.wales/use-of-site/privacy-notice](http://phw.nhs.wales/use-of-site/privacy-notice)
- email [PHW.InformationGovernance@wales.nhs.uk](mailto:PHW.InformationGovernance@wales.nhs.uk), or
- phone 029 2010 4307.

We also keep personal details to make sure that the standard of our service is as high as possible. This includes checking your baby's records if your baby is found to have a condition after having a screening test which showed a 'not suspected' result.

We only ever publish information as statistics and we never publish personal details. We pass on your personal information to health professionals or organisations that need it, including your GP, health visitor and consultant paediatrician. These professionals must protect the personal information in the same way as we do.

All our paper and computer records are stored and processed securely, and the public cannot access them.



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