

Testing for potential increased risk of hearing loss with aminoglycoside antibiotics

Information for people with cystic fibrosis

November 2023



Contents

What are aminoglycoside antibiotics?	3
What is the <i>MT-RNR1</i> blood test?	3
Why is the <i>MT-RNR1</i> test needed?	3
Who needs the <i>MT-RNR1</i> test?	4
How do I get the <i>MT-RNR1</i> test?	4
What is involved and what happens after the test?	4
Important things to remember	4
Further information	5

Key points

- Aminoglycosides are a group of antibiotics used to treat certain infections. Permanent hearing loss is one possible side effect that may be caused by aminoglycoside antibiotics.
- The *MT-RNR1* test looks at your DNA (a biological molecule in the body that stores genetic information) to check if you have a variant (mutation) in the *MT-RNR1* gene that means you are at an increased risk of experiencing hearing loss with aminoglycoside antibiotics.
- The *MT-RNR1* test is useful for people with long-term conditions, such as cystic fibrosis (CF), which mean they are likely to need aminoglycoside antibiotics in the future. You should attend any appointments to monitor your hearing after treatment with aminoglycosides, even if you do not have a variant in the *MT-RNR1* gene. This is because the *MT-RNR1* gene variant is only one possible cause of increased risk of hearing loss with aminoglycosides.

You should talk to your CF team if you have any questions about *MT-RNR1* testing or medication side effects.

What are aminoglycoside antibiotics?

Aminoglycosides are a group of antibiotics used to treat certain infections. They include the antibiotics amikacin, gentamicin, and tobramycin.

Aminoglycosides have been used for many years to treat infections in people with cystic fibrosis (CF). Like most medicines, aminoglycosides can cause side effects. These may be different in different people. Not everyone who receives treatment with aminoglycoside antibiotics experiences side effects. This leaflet focuses on the specific side effect of hearing loss, that may be caused by aminoglycoside antibiotics.

Your CF team carefully considers which is the right antibiotic for you and will talk to you about the risks and benefits of any treatment you need. The risk of hearing loss may be worrying for people who need aminoglycosides to treat an infection. If you need aminoglycoside antibiotics, your CF team will check your hearing regularly and will also take blood tests to try and reduce the risk of hearing loss. Talk to your CF team if you are feeling anxious about your hearing.

If you've got any concerns or questions about side effects with these or any other medicines, please contact your CF team.

What is the *MT-RNR1* blood test?

A small number of people have a greater chance of developing hearing loss with aminoglycoside antibiotics than others, which may be explained by a variant in their DNA. The *MT-RNR1* test looks at your DNA, which can be taken from a blood sample, to check if you are at an increased risk of experiencing permanent hearing loss with aminoglycosides. The one-off blood test looks for a specific variant in the section of DNA, or gene, known as *MT-RNR1*. This variant can be found in people with CF or without CF, and is separate from the variants in the gene that cause CF.

Why is the *MT-RNR1* test needed?

Around **1 in 500** people have a variant in their *MT-RNR1* gene which means they are more likely to experience hearing loss with aminoglycoside antibiotics.



The test result will help your doctors choose the best antibiotic for you. It is important to know that aminoglycosides might still cause permanent hearing loss in people who do not have the *MT-RNR1* gene variant. This is because there are other, more common ways aminoglycosides cause hearing loss, which are not detected by the *MT-RNR1* test. This is why your CF team will check your hearing regularly and take blood tests if you need aminoglycosides, whether you have the *MT-RNR1* gene variant or not.

Who needs the *MT-RNR1* test?

The *MT-RNR1* test is suitable for the following groups of people.

- People with long term conditions, such as CF, which mean they are very likely to need aminoglycoside antibiotics in the future.
- People who have had treatment with aminoglycoside antibiotics in the past and now have hearing loss.

The *MT-RNR1* test must be done well in advance of you needing aminoglycoside antibiotics. It is not suitable for situations where antibiotics need to be started quickly to treat an infection. This is because the result of the test can take up to six weeks to come back.

If you have been treated with aminoglycoside antibiotics before and have not experienced hearing loss, your CF team will decide whether the *MT-RNR1* test may be helpful to inform your future treatment options.

How do I get the *MT-RNR1* test?

Your CF team will discuss with you if they are taking a blood sample for the *MT-RNR1* test. The test might be done on its own, or at the same time as other genetic testing. If you've not been tested, but think you should have this test done, discuss this with your CF team at your next appointment or at your annual review.

What is involved and what happens after the test?

The *MT-RNR1* test is a simple blood test. Your CF team will let you know your result, which can take up to six weeks. If your test shows that you are at an increased risk of hearing loss with aminoglycoside antibiotics, it will be recorded in your medical notes. It is also important to mention this to healthcare professionals in the future when you are receiving treatment.

The *MT-RNR1* gene variant runs in families. Your doctor may ask you for details of other members of your family and may give you an appointment to discuss this with the genetics service.

Talk to your CF team if you have any questions about *MT-RNR1* testing or medication side effects.

Important things to remember

- The *MT-RNR1* test looks at your DNA to check if you are at an increased risk of experiencing hearing loss with aminoglycoside antibiotics.
- The *MT-RNR1* gene variant is only one possible cause of increased risk of hearing loss with aminoglycosides.
- You may still experience hearing loss if you are receiving treatment with aminoglycosides even if your *MT-RNR1* test results show you do not have the gene variant.
- You should attend any appointments to monitor your hearing after treatment with aminoglycosides, even if you do not have the *MT-RNR1* gene variant.

Further information

Find more information resources about living with cystic fibrosis at cysticfibrosis.org.uk/information.

Our Helpline is open 10am – 4pm Monday to Friday. It's available to anyone looking for information or support with any part of cystic fibrosis, a listening ear, or just to talk things through.

How to reach us:

- Call **0300 373 1000** or **020 3795 2184**
- Email helpline@cysticfibrosis.org.uk
- Chat with us on **Facebook, Twitter or Instagram**
- Message us on WhatsApp on **07361 582053**

Visit cysticfibrosis.org.uk/helpline for more information.

We welcome your feedback on our resources.

You can also ask for this resource in large print or as a text file. Email infoteam@cysticfibrosis.org.uk.

Cystic Fibrosis Trust
2nd Floor One Aldgate
London
EC3N 1RE
020 3795 1555

cysticfibrosis.org.uk

This leaflet was written by Paul Selby, Clinical Pharmacy Lead, NHS East Genomic Medicine Service Alliance; Rachel Palmer, Lead Genomics Pharmacist, NHS South West Genomic Medicine Service Alliance; Kate North, Genomics Project Pharmacist, North Bristol NHS Trust; Dr Simon Langton-Hewer, Consultant Respiratory Paediatrician, Bristol Royal Hospital for Children; and Emily Dustan, Paediatric Pharmacist, Bristol Royal Hospital for Children.

© Cystic Fibrosis Trust October 2023.
Next review due: October 2026

You can copy any information from this resource without our permission. You must not make money from it and you must acknowledge the Cystic Fibrosis Trust as the original author.

The information in this resource does not replace any advice from your doctor or CF team. It is important that you seek your team's advice whenever you want to change your treatment.

Cystic Fibrosis Trust

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.

cysticfibrosis.org.uk

© Cystic Fibrosis Trust 2023. Registered as a charity in England and Wales (1079049) and in Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: 2nd Floor, One Aldgate, London EC3N 1RE.

Uniting for a life *unlimited*