

Testing for potential increased risk of hearing loss with aminoglycoside antibiotics

Information for people with cystic fibrosis

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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 variants (mutations) 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), where aminoglycoside antibiotics are often used to treat infections. You should attend any appointments to monitor your hearing after treatment with aminoglycosides, even if you do not have any variants in the *MT-RNR1* gene. This is because the *MT-RNR1* gene variants are 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 carry out blood tests to try to understand your risk of experiencing side effects from aminoglycoside antibiotics, including hearing loss, and reduce it. 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 variants 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 specific variants in the section of DNA, or gene, known as *MT-RNR1*. These variants 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 variants 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 variants. 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 variants 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 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 variants run 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 variants are 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 variants.
- You should attend any appointments to monitor your hearing after treatment with aminoglycosides, even if you do not have the *MT-RNR1* gene variants.

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.

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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.



Our resources are free to download and order, but we would be very grateful if you would consider **making a donation** to help us continue our important work. Visit cysticfibrosis.org.uk/donate

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