Treatment-free remission for chronic myeloid leukaemia (CML)

Treatment-free remission (TFR) is when your CML stays under control without the need to keep taking medicines. It might be possible for some people with CML who have a deep, long-term response to tyrosine kinase inhibitors (TKIs). Find out about the risks and benefits, and what happens if you try it.

Summary

Do not stop CML treatment without discussing it with your haematology team.

- Treatment-free remission (TFR) is when your CML stays under control without the need to keep taking medicines.
- It might be an option for people who have been taking TKIs for 3 to 5 years or more and have been in a deep molecular response for at least 2 years.
- If TFR is an option for you, your haematology team should talk to you about the benefits and drawbacks. You should decide together if it's something you'd like to try.
- If you try TFR, you have regular check-ups to monitor your response.
- Around 50 or more in every 100 people who try TFR keep their response to treatment. But up to 50 in every 100 people may lose their response.
- If you lose your response to treatment, restarting TKI treatment is usually very effective.
- Around 20 to 30 in every 100 people who stop TKIs get muscle pain and joint stiffness. This is called treatment discontinuation syndrome. It usually goes away on its own, but some people might need a short course of treatment.

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What is treatment-free remission?

Treatment-free remission (TFR) is when your CML stays under control without the need to keep taking medicines. It may be possible for some people with CML who have had a deep, long-lasting response to treatment with tyrosine kinase inhibitors (TKIs).

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Who may be able to try TFR?

TFR is not possible for everyone. But it might be an option if:

- Your CML is in the chronic phase and has never been in the blast phase.
- You've been on TKI treatment for at least 3 years (but ideally 5 years)
- You've been in a deep molecular response for at least 2 years.
- You've never had to stop taking a TKI because it didn't work well. (You might still be able to try TFR if you had to stop a TKI because of side effects.)
- You do not have a genetic change in your *BCR-ABL1* gene that makes it resistant to treatment.
- Your hospital has quick access to accurate molecular testing (PCR) to monitor your CML.

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Benefits and drawbacks of TFR

If TFR is an option, your haematology team should talk to you about the benefits and drawbacks. You should decide together whether it's something you'd like to try. If you feel anxious and you are not comfortable trying it, let them know. Your haematology team shouldn't force TFR on you if you are not comfortable with it.

Benefits of trying TFR

- Your CML might stay under control without having to take any medicines. This is the case for around 50 or more in every 100 people who try TFR.
- You do not have to remember to take medicines every day.
- You are not at risk of getting any side effects.

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- If you are hoping to get pregnant, TFR might give you the chance to do this safely and stay off TKI treatment during your pregnancy.

Drawbacks of trying TFR

- Your CML might not stay under control. This happens in up to 50 in every 100 people who try TFR. It usually happens within 6 to 9 months of stopping treatment, although it can happen much later. If your CML does not stay under control, you will need to start treatment again.
- You have more frequent blood tests and appointments to check if your CML is staying under control.
- You may get treatment discontinuation syndrome.
- You may feel anxious about your CML coming back.

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What does TFR involve?

If you and your haematology team agree that TFR is right for you, they will explain what the process will involve.

- You might stop your TKI treatment straightaway, or you might take a half-dose for a year before stopping treatment. This may improve the chance of your CML staying in under control once you stop treatment.
- You will have frequent blood tests to check your molecular response. You will also have check-ups to look for treatment discontinuation syndrome.

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Treatment discontinuation syndrome

Treatment discontinuation syndrome is muscle pain and stiffness that develops after you stop treatment with TKIs. Around 20 to 30 in every 100 people who stop TKIs get it. Doctors do not know exactly why it happens. It usually starts within days or weeks of stopping your TKI.

Treatment discontinuation syndrome is usually mild and goes away on its own. But some people may need a short course of treatment with paracetamol, non-steroidal anti-inflammatory medicines like ibuprofen or diclofenac, or sometimes steroids (prednisolone).

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If CML does not stay under control

If you try TFR, your haematology team will monitor your molecular response closely. If you lose a major molecular response, you will usually need to start treatment again. This should happen within 4 weeks of losing your response. Most people restart the same TKI they were on before, but your haematologist might suggest a different one.

If you do not achieve a major molecular response within 6 months of restarting treatment, your doctor is likely to check for changes in your *BCR-ABL1* gene. These could affect how well it responds to treatment. They might suggest a different treatment option.

> **It can be very worrying if your CML does not stay under control, but restarting TKI treatment is usually very effective.**

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