



Northumbria Healthcare
NHS Foundation Trust

Stopping treatment for Chronic Myeloid Leukaemia (CML)

Issued by the haematology department

You have been given this leaflet as you are taking medication for chronic myeloid leukaemia. This includes drugs called Imatinib, Nilotinib or Dasatinib.

You have also had an undetectable level of BCR-abl (blood test measurement of your response to this treatment) for 2 years or more. This is known as a complete response.

There is growing evidence that many patients who meet the criteria above can stop treatment. This may be for a period of time or long term.

What are the benefits of this?

If you decide to stop treatment, this means you will not have to take tablets for your CML every day. This may improve the side effects you might have experienced from this treatment, without having an overall impact on your CML long term.

For the first six months after stopping, the haematology team (your consultant, pharmacist or nurse) will check your BCR-abl levels every month. For the next six months we will check it every two months. After this, you may be able to return to three monthly monitoring. This monitoring pattern helps us check your BCR-abl results closely when you are not on treatment. About 40% of patients remain off treatment for two years or longer.

What are the risks of this?

Some patients who stop treatment will start to show a rise in their BCR-abl levels. This happens in about 60% of patients. This will be identified at an early stage due to the close monitoring after you stop treatment. This is safe, several studies show that when treatment was restarted, 100% of patients responded.

Do I have to stop treatment?

Not at all, this is your decision and you will be supported by your Haematology team. If you want to stop treatment please discuss this during your clinic appointment or contact the department via the numbers overleaf before stopping.

What if I want to re-start treatment?

You can discuss this at any time, either during a clinic appointment or with the haematology team via the numbers overleaf. This is your right. If you have made a decision to stop treatment previously this will not affect your access to this treatment in the future, and you will be able to re-start it if you want to.

Who can I contact if I have questions?

Please contact your haematology team at either Wansbeck, North Tyneside or Hexham via the hospital switchboard 0344 811 8111 or talk to your haematologist, haematology pharmacist or nurse in clinic.

Where can I find more information?

Bloodwise <https://bloodwise.org.uk/> 0808 2080 888

Macmillan <https://www.macmillan.org.uk> 0808 808 0000

CML support <https://cmlsupport.org.uk/>

Alternative Formats

If you would like a copy of this information in large print, another language, audio tape or other format please call the Contact Centre on 03 44 811 8118.

Other sources of information

NHS 111

NHS Choices

www.nhs.uk/pages/homepage.aspx

NICE (National Institute for Health and Clinical Excellence)

www.nice.org.uk

Patient Advice and Liaison Service (PALS)

Freephone: 0800 032 0202

Text: 07815 500015

Email: northoftynepals@nhct.nhs.uk

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General Enquiries 03 44 811 8111

www.northumbria.nhs.uk

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