

## Patient information factsheet

# Teenage and young adult (TYA) cancer care Maintenance chemotherapy for acute lymphoblastic leukaemia (ALL)

You have been given this factsheet because you are due to start maintenance chemotherapy for acute lymphoblastic leukaemia (ALL). This factsheet explains what is involved. If you have any questions or concerns about anything covered in this factsheet please speak to a member of your healthcare team or your TYA clinical nurse specialist (CNS).

### What is maintenance chemotherapy?

Maintenance chemotherapy is the last phase of ALL treatment. It helps to keep the leukaemia in remission. It is designed to be given in an outpatient setting, so that patients don't need to stay overnight in hospital, with most being able to return to their usual lifestyle and activities while receiving ALL treatment.

### What is the aim of this phase of treatment?

- The aim of this phase of treatment is to keep leukaemia in remission by taking continuous daily oral chemotherapy.
- The tablets are taken at a dose that will not cause severe neutropenia (very low neutrophil counts) or thrombocytopenia (low platelets counts). This is an important point as low blood counts can cause infections, bleeds, or other undesirable side effects. This factsheet tells you what you need to know.

### Why do I need to have this treatment?

In the past, when leukaemia was first treated, patients did not receive maintenance chemotherapy and in many cases, the leukaemia came back. Relapsed leukaemia is harder to treat, and so to prevent this, extra chemotherapy treatment was added. 'Maintenance' chemotherapy is effective at keeping the leukaemia away in most people, but only if it is taken every day. Males need longer treatment than females.

### How is it given?

You will be given several drugs on a three-month cycle that is repeated for about two years (females) or three years (males).

The drugs you will be given are:

#### **Mercaptopurine (6MP) - to be taken once daily.**

- The dose will change depending on your blood count. The aim is to keep the neutrophils between 0.75 and 1.5 all the time and/or platelets between 75 and 150.
- If they fall, your doctor will reduce the mercaptopurine dose - every person needs different

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amounts.

- The drug comes in 50 mg and 10 mg tablets. (If your dose is 70 mg daily, for example, you need to take 1 x 50 mg and 2 x 10 mg tablets). Always check and remember your current dose in milligrams (mg).

## **Methotrexate (MTX) - to be taken once a week** (on the same day).

- Pick a day that is easy to remember that is not the same day as co-trimoxazole.
- It should also be missed on the week when methotrexate chemo is given through a lumbar puncture (for example, in the week of your intrathecal chemotherapy which is given every 3 months).
- The drug comes in 2.5 mg tablets. Ensure you are taking the correct number of tablets.
- You must avoid NSAIDs (non-steroidal anti-inflammatory drugs for example, ibuprofen, aspirin and diclofenac) while taking this medication.

## **Dexamethasone** (a steroid), **to be taken twice a day** (morning and lunchtime) for **five consecutive days, every 28 days**.

### **Dexamethasone side effects include:**

- mood changes
- irritability
- poor concentration

Please talk to a member of your healthcare team if you have any concerns about side effects.

## **Vincristine - once every 28 days by an intravenous injection on the TYA unit.**

This chemotherapy treatment is combined with 5 days of oral dexamethasone.

### **Vincristine side effects can include:**

- constipation
- cramps
- jaw pain
- numb/tingling fingertips

Please talk to a member of your healthcare team if you have any concerns about side effects.

### **Every month, when you come to receive Vincristine:**

- You will be seen by a doctor and your current mercaptopurine and methotrexate doses will be confirmed in milligrams (mg).
- You will be given a further month's worth of mercaptopurine, methotrexate and other supportive medications, such as co-trimoxazole and antivirals (aciclovir), to take home. Remember to get this from the TYA unit nurses or outpatients pharmacy.
- If you are unclear about any of the chemotherapy doses, please ask.

### **Vincristine blood tests:**

- You will have a blood test each month when you come in for your Vincristine appointment.
- You will also need to have a blood test one week before. This can be done at your local hospital if it is more convenient for you.
- This blood test is important because your doctor needs to see your most current blood test result to prescribe the correct dose of mercaptopurine and methotrexate for you.
- If this is missed or not done it is likely to cause delays with your Vincristine treatment

as our pharmacist will also need to see your blood test results before releasing the chemotherapy.

- Your TYA CNS can help you to book your blood test and get the results to your doctor.
- Sometimes you may need to have additional blood tests on a date advised by your doctor. This is to see that you are receiving the correct dose of your chemotherapy and that there are no concerning side effects.

## Does it matter if I miss a dose?

Yes. It has been shown that missing your tablets can increase the risks of leukaemia coming back. If the leukaemia comes back (relapse), this may involve much more intensive inpatient treatment and in many cases a bone marrow transplant (receiving bone marrow from another person and having severe immune suppression). It is important that all steps are taken to stop it coming back and to keep you in remission.

However, if you are told by your doctor to miss a few doses then it is OK.

## You will always be told:

- how many days you need to stop your chemotherapy for
- when to have a blood test
- when it is safe to restart taking your chemotherapy. (This may be because your counts are low, because of infections or the chemotherapy is causing bad side effects. Research has shown this does not increase the relapse risk).

We will always advise you if any changes need to be made, please do not amend your dosage without talking to us.

## Concerns about your ALL medications or dosage errors

If you have any concerns that you have not taken your medication correctly or have taken the wrong dose, please seek advice from your clinical nurse specialist (CNS) team as soon as possible. Out of hours, contact the acute oncology service 24-hour helpline: **023 8120 1345**.

## Supportive medications

**Co-trimoxazole** (brand name Septrin) - an antibiotic is used to prevent certain rare, but dangerous, types of chest infection.

- it should not be taken on the same day as methotrexate
- some people have a monthly nebuliser (Pentamidine) instead

**Aciclovir** - an antiviral to protect against cold sore and shingles virus.

## Tips for taking your chemotherapy

- Make sure you have enough at home.
- Pick it up monthly and let your nurse know if you will run out.
- You can buy a weekly pill box for around £2 from any chemist.
- Ask to be accountable to a family member or friend.
- Tell us about bad side effects. We can help stop some of them.
- Your specialist nurse can text reminders if that helps.
- If you are struggling, please ask for help.

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## Contact us

TYA clinical nurse specialist (CNS) team: **07920 708342** (8am to 6pm, Monday to Friday).  
Acute oncology service (24-hour helpline): **023 8120 1345**

## Useful links

[www.macmillan.org.uk](http://www.macmillan.org.uk)

[www.cancerresearchuk.org](http://www.cancerresearchuk.org)

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