

Patient information factsheet

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

What is maintenance chemotherapy?

The last phase of ALL treatment is maintenance therapy. It helps to keep the leukaemia in remission. This factsheet tells you what you need to know.

Why do I need to have it?

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 chemo was added. 'Maintenance' chemo is effective at keeping the leukaemia away in most people - but only if it is taken every day, and men need longer treatment than women.

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). These are:

Mercaptopurine (6MP) a tablet taken every day. 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. If they fall, your doctor will reduce the 6MP dose - every person needs different amounts. This is chemotherapy and stops leukaemia returning.

Methotrexate (MTX) once a week tablet. Pick a day that is easy to remember that is not the same day as Septrin. It should also be missed on the week when MTX is given through a lumbar puncture (week 3 of the cycle). This is chemotherapy and stops leukaemia returning. (A lumbar puncture is a procedure in which a hollow needle is inserted between the bones of the lower back and into the fluid around the lower part of the spinal cord).

Dexamethasone (DEX) you will take this steroid drug twice a day for five consecutive days every 28 days. Side effects include mood changes/irritability/poor concentration. This stops leukaemia coming back, especially when given with vincristine. There is a clinical trial looking at whether this is as important as the other tablets, we don't know the answer yet.

Co-trimoxazole (brand name Septrin) is an antibiotic and is used to prevent certain types of pneumonia (swelling of the tissue in one or both lungs). This should not be taken on the same day as methotrexate. Some people have a monthly nebuliser (Pentamidine) instead.

Vincristine (VCR) you will usually have this chemotherapy drug once every 28 days by an intravenous injection at the same time as the dexamethasone. Side effects can include constipation, cramps and numb fingertips.

Does it matter if I miss a dose?

Yes. It has been shown that even missing one tablet every two weeks possibly doubles the risk of the leukaemia coming back. If the leukaemia comes back (relapse), this will involve much more intensive

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inpatient treatment and 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 doses then it's ok. This may be because your counts are low or the chemo is causing problems – research has shown this does not increase the relapse risk.

We will always ring you if any changes need to be made, please do not self-dose.

Tips for taking your chemo

- Make sure you have enough at home - pick it up monthly and let your nurse know if you will run out.
- Use the Macmillan alarm app to remind you.
- 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 stop some of them.
- Your specialist nurse can text reminders if that helps.
- If you are struggling, please ask for help.

Who to contact

TYA nurse specialist: **07920 708342**

Acute oncology service (24-hour helpline): **07867 973649**

Useful links

www.macmillan.org.uk

www.cancerresearchuk.org

If you need a translation of this document, an interpreter or a version in large print, Braille or on audio tape, please telephone 023 8120 4688 for help.