Ciclosporin used as part of Anti-Thymocyte Globulin (ATG) treatment
This information leaflet is for patients who have been prescribed ciclosporin as part of immuno-suppressive treatment (IST) that is given with Anti-Thymocyte Globulin (ATG). It explains what it is, how it works and any potential side effects or complications.

What is ciclosporin?
In patients who suffer from aplastic anaemia, the immune system misinterprets signals and wrongly attacks the stem cells, that make all of the blood cells in the body.

Ciclosporin is an immunosuppressant medicine which has been used for many years to treat aplastic anaemia. It works by restricting the way your immune system reacts against your own bone marrow, suppressing or quietening down your immune system to help your bone marrow heal and recover. As the immune system is suppressed, there is an increased risk of certain types of infections including viral infections while you are taking this drug. But this risk is small for most patients with aplastic anaemia who take ciclosporin.

The medicine comes in various forms:
• as capsules, which you are most likely to be given
• as a liquid
• intravenously, when the drug is administered directly into a vein, usually in your arm

Why do I need to take ciclosporin?
Ciclosporin can be used on its own as a treatment, but if you have aplastic anaemia it works better when given with Anti-Thymocyte Globulin (ATG). Ciclosporin is most often given with ATG but is also sometimes used on its own, if there is a medical reason why ATG is not appropriate for a particular patient.
How long do I have to take it?

You will take ciclosporin for at least six months and usually longer than that. Your blood counts will be checked regularly to see if they are improving. By ‘blood counts’ we mean:

- your haemoglobin (Hb) level, which is a measure of the number of red cells you have in your blood
- your white blood cells
- your platelets

A response to immunosuppressant treatment (such as the drug ciclosporin) in patients with aplastic anaemia, takes time, usually at least 3-4 months. The clinical team will decide the right dose of Ciclosporin based on your blood test results. Even after a response has been seen (that is, your blood counts are improving) treatment needs to be continued with Ciclosporin. Your doctors will determine when you can start tapering or reducing the dose of Ciclosporin you take. The amount of ciclosporin you take will then be reduced very slowly over a period of many weeks to months.

As the dose is reduced your blood counts will be closely monitored to ensure they remain stable. If your blood count does not improve, your doctor will talk to you about having different treatment for your aplastic anaemia.

It is important that you do not stop taking ciclosporin suddenly or reduce the dose too quickly or too early. This is because it will increase the risk of aplastic anaemia coming back, which is known as a ‘relapse’.

Did you know?

You start taking ciclosporin on the first day of your ATG treatment. The usual dose is given twice a day.

Key facts

6 months

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3-4 months

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What dose do I take?

Your dosage is worked out according to your weight. When this amount has been worked out, it is divided into two doses – one for the morning, the other for the evening. By taking it twice a day, the levels of ciclosporin in your bloodstream will remain steady.

The level of ciclosporin in your blood will be checked regularly, as well as other bio-chemical tests from your blood results that inform about your liver and kidney functions. Your dosage level may change depending on these results. Your ciclosporin levels can be affected by other drugs that you may need to take. But do not stop taking any prescribed medicines unless your doctor advises you to do so.

Did you know?

It usually takes at least three to four months before a response is seen in aplastic anaemia, for patients treated with IST (drugs such as ATG and ciclosporin).

What are the possible side effects?

Ciclosporin has a number of possible side effects, which is why your blood counts will be regularly monitored. Because high levels of ciclosporin in your blood can increase the risk of side effects, you will be asked to take a lower dose if your level is found to be too high.

**Common** side effects that you may get soon after starting ciclosporin include:
- nausea (feeling sick), vomiting (being sick) and poor appetite, often within the first couple of weeks but then settling down
- raised blood pressure – you may need to take medicine to control your blood pressure while taking ciclosporin
- muscle cramps
- burning sensation in your hands or feet
- headaches
- weight gain because your body retains fluid, an effect known as ‘oedema’
- increased hair growth, including facial hair
- thickening of your gums
- fine tremors (shaking) in your hands
- abnormal kidney blood results

**Rare** side effects include:
- fits/seizures and confusion
- numbness or pins and needles (neuropathy)
- an increase in your cholesterol levels
- an increase in your blood potassium levels
- a reduction in your blood magnesium levels
- gout

**Very rarely,** taking ciclosporin can lead to tumours such as lymphoma (a tumour of the lymph glands) but this is only a very slight risk.

In men, gynaecomastia, which causes breasts to develop or some tender swelling in that area
Are there any alternative treatments?

Other drugs that are used to treat aplastic anaemia include ATG (ciclosporin is often combined with ATG treatment, but can also be given independently) and eltrombopag, but your doctor will discuss these with you.

Can I take other medicines with ciclosporin?

Many drugs interact with ciclosporin and you should always tell any doctor treating you that you are on treatment with ciclosporin. Do not take over-the-counter/non-prescription or herbal medicines without discussing this first with your doctor, nurse or pharmacist. However, many drugs can be taken safely with ciclosporin.

Is there anything I should avoid while taking ciclosporin?

Avoid:

- grapefruit juice. This increases the amount of the drug in your blood as it helps your body to absorb it, leading to an increase in the risk of side effects
- lipid controlling drugs, especially statins. These can interact with ciclosporin and cause serious damage to your muscles as well as kidney failure
- some herbal remedies, such as St John’s Wort. These can reduce the level of ciclosporin in your blood and may stop it from working properly

Do I need any special checks while on ciclosporin?

It is very important that your blood pressure is checked regularly. Your kidney and liver blood tests and ciclosporin blood levels also need to be monitored regularly, alongside monitoring of your blood counts.

Can I have vaccinations while on ciclosporin?

This is something you should discuss with your haematology consultant first. Some vaccinations have been linked to relapse of aplastic anaemia. Do not have any ‘live’ vaccines such as polio, rubella (German measles) or yellow fever.

Further information

The following patient information fact sheets are available free of charge from the Aplastic Anaemia Trust:

- Going into hospital for a course of Anti-Thymocyte Globulin (ATG)
- Steroids used as part of Anti-Thymocyte Globulin (ATG) treatment
- Clean Diet

You can download them from our website www.theaat.org.uk or request copies by phone or email. Contact details can be found on the inside cover of this fact sheet.
Your notes and questions
Please use this page to write down any questions you want to ask your medical team.
The Aplastic Anaemia Trust is the only UK charity dedicated solely to research into aplastic anaemia and the support of patients and their families.

We provide emotional support as well as expert, up-to-date information about aplastic anaemia and the treatments available.

For more information, please contact:

The Aplastic Anaemia Trust
PO Box 317
St Neots
PE19 9GA

0300 102 3202
support@theaat.org.uk
theaat.org.uk

This fact sheet has been produced using information kindly provided by King’s College Hospital, London.