Essential Thrombocythaemia (ET)

What this leaflet is about: too many platelets, why bleeding and clotting are both risks, and how it is treated.

> Quick emergency advice
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> Persistent bleeding that will not stop, a new painful swollen calf, or sudden breathlessness: seek medical help.
> Sudden weakness or numbness on one side, or sudden blurred vision: treat as a stroke and call for help immediately.

What is essential thrombocythaemia?

Essential thrombocythaemia (ET) is a condition in which the bone marrow makes too many platelets. Platelets help blood to clot, so too many of them can make the blood stickier. ET is a type of myeloproliferative neoplasm (MPN).
It is usually driven by a change in one of three genes - JAK2, CALR or MPL - found with a simple blood test. ET usually develops slowly and often stays mild for years.

How will I feel?

Many people have no symptoms. If symptoms occur, they are usually mild and come and go:

- Tiredness.
- Headaches and a feeling of fullness in the head.
- A tingling, burning orpins-and-needles feeling in the hands or feet, often worse in the evening or in warmth.
- Visual disturbance, such as blurring or a flickering shadow.
- Bruising or a nosebleed that takes longer than usual to stop.

> Tell your doctor straight away about any new or persistent bleeding, or if you have burning pain or redness in a leg.

Why can ET both clot and bleed?

This surprises people. Although the platelet count is high, very large numbers of platelets can interfere with the normal clotting process, so minor bruising and nosebleeds are common. At the same time the blood remains stickier than normal, so clots can still form in the arteries or veins. Both risks are real, and both depend on how high the count is and your other risk factors.

How is ET treated?

- Observation only - very low risk ET is often simply monitored with regular blood tests, sometimes with low-dose aspirin.
- Low-dose aspirin - unless you have a particular reason not to take it.
- Hydroxyurea - a tablet, for people at higher risk of clotting or bleeding.
- Interferon - given by injection, often preferred in younger people and in pregnancy, because it is safer for the baby.
- JAK inhibitors such as ruxolitinib - used if ET progresses to myelofibrosis.

If you are pregnant or planning a pregnancy

Tell your team early. Interferon is generally preferred because it does not harm the baby, and aspirin is usually stopped. Do not stop any medicine on your own - contact the clinic first.

Will it change?

ET is monitored over the long term. A minority of people develop myelofibrosis, where the marrow becomes scarred, or acute myeloid leukaemia. Keeping your blood tests and appointments matters even when you feel completely well.

Look after yourself

- Report fevers or temperatures of 38 degrees C or above the same day.
- Be careful with knives, gardening and contact sports when your count is low or you are bruising.
- Use a soft toothbrush and an electric razor.
- Avoid taking aspirin or ibuprofen for everyday aches unless your doctor has told you to - ask first.

Where to read more

The US National Cancer Institute and the American Cancer Society publish public patient information on essential thrombocythaemia. Ask us for the printed links.

When to contact us

If you are worried about yourself, or about the person you are caring for, please get in touch. We would always much rather hear from you early than late. If you have read something in this leaflet that worries you, that is a good reason to telephone us, even if you feel well.

Visit us
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If you cannot reach us, or you are very unwell

Please go to the emergency department of KPJ Ampang Puteri Specialist Hospital, or call the emergency ambulance service. Do not wait for a routine appointment, and do not wait for a reply to an email.

Important medical disclaimer

This leaflet is written for patients and their families and carers. It is general patient education only. It is not a substitute for medical advice, and it is not a substitute for the diagnosis and treatment that your own haematologist, nurse, pharmacist or doctor will give you.

Nothing in this leaflet should be used to change, stop or start a medicine, a test or a treatment. If anything you read here is different from what your healthcare team has told you, follow your healthcare team and ask us about the difference.

Information about medicines names, strengths, test turnaround times and supportive care is current at the time this leaflet was prepared. It may be updated from time to time, and the version printed here may therefore not be the newest one. Please ask reception for the current copy.

If you think that you or someone you care for is seriously unwell, do not wait for an appointment and do not wait for this leaflet to be read. Contact the clinic, or go to the emergency department of KPJ Ampang Puteri Specialist Hospital, straight away.

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