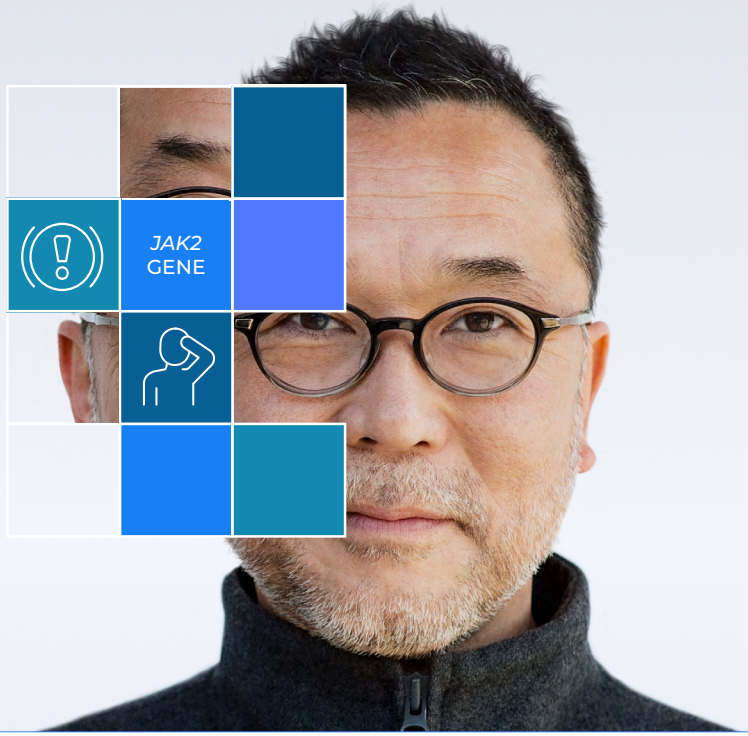
PIECE TOGETHER ET



PIECE TOGETHER ET GUIDE

A diagnosis of essential thrombocythemia (eh-SEN-shul throm-bo-sy-THEE-mee-uh), or ET, can feel confusing—especially when symptoms are vague or counts look "fine." But putting the pieces together can empower you to understand what's really happening, recognize symptoms and risks, and feel more confident partnering with your doctor to make informed, proactive decisions about your health.

This guide includes:

- Key facts about ET
- Common symptoms
- Risks and complications

Speak up and be your own advocate for the long term

ET is a chronic cancer, and your needs may change over time. Doctors bring medical expertise, but you bring your lived experience—and both matter. Continue to check in with yourself, share what's new, and speak up when something feels different. You know your body best, and your voice is an essential part of your care.

Piecing together the facts about ET

What is ET?

Essential thrombocythemia is a rare, chronic blood cancer. It belongs to a group of bone-marrow cancers known as myeloproliferative neoplasms, or MPNs.

- In ET, the bone marrow makes too many platelets
- When platelet levels are high, the blood can be more likely to clot and may lead to serious health problems, such as a stroke, heart attack, or pulmonary embolism

What causes ET?

ET develops when stem cells in the bone marrow develop a genetic mutation (or DNA change) that causes it to make too many platelets.

- Nearly 2 out of 3 people with ET have a mutation in a gene called *JAK2*
- This mutated gene sends faulty messages in the bone marrow, causing platelet-producing stem cells to make more platelets than your body needs

Is ET genetic or inherited?

Typically, ET is not inherited. These genetic mutations usually happen during a person's lifetime for unknown reasons.

How common is ET?

In the United States, about 1.5 to 2.5 people out of every 100,000 are diagnosed with ET each year.

About 24 out of every 100,000 people in the United States are currently living with ET.

ET is most often diagnosed later in adulthood. The average age of diagnosis is around 60 years.

ET can occur in younger people. About 20% of people with ET are diagnosed before age 41.

ET is more common in females than males, with women diagnosed about twice as often as men.

Speaking up about ET symptoms

Many symptoms of ET can be vague, mild, and easy to miss or brush off. Some people don't experience symptoms at all. Because these changes develop gradually, ET is sometimes discovered only through routine blood tests rather than noticeable warning signs.

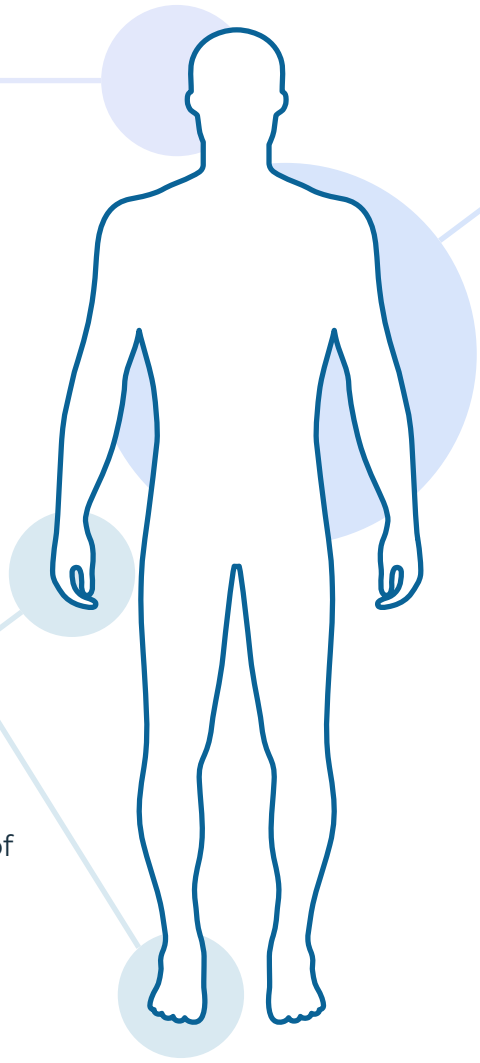
If you're living with ET, talk openly with your doctor about how you're feeling, even if the changes seem minor or hard to explain. Every detail helps your care team understand the full impact of ET and guide your treatment decisions.

Head

- Fatigue
- Headache
- Dizziness
- Blurry or distorted vision

Hands and feet

- Burning, redness, or pain in hands or feet
- Coldness or blueness of fingers or toes



General symptoms

- Easy bruising, nosebleeds, or heavy menstrual periods
- Blood in your stool or urine
- Shortness of breath, chest pain, or cough
- Nausea
- Slurred speech
- Sleep problems
- Sexual problems
- Itching

Track how you're feeling: Scan the QR code or visit PieceTogetherET.com/resources for a printable symptom tracker to help you prep for talking with your doctor.

Making sense of risks and complications

Understanding both the short- and long-term risks can help you and your doctor create a care plan that supports your health, reduces the chance of complications like blood clots, and helps monitor for signs that the disease may be getting worse, also called disease progression.

Risk of blood clots with ET

Reduced or abnormal blood flow in ET can increase the risk of developing blood clots, also called thrombotic complications or thrombotic events. These clots can lead to serious complications such as stroke, heart attack, deep vein thrombosis (DVT), or pulmonary embolism—a blood clot that travels to your lungs.

- Thrombotic complications occur in 9%-84% of people at diagnosis
- 7%-32% of people experience a clot during the follow-up period
- People who have had one clot are more likely to have another one
- After the first clot, the next one can occur sooner—sometimes within months

Progression to other cancers

With proper treatment, many people with ET can continue to live full, active lives. However in some cases, ET can turn into more aggressive cancers over time. These other forms of cancer include:

Myelofibrosis (MF)
Over time, ET can transform into MF, a related cancer that causes scarring in the bone marrow. When this happens, the marrow can no longer make healthy blood cells. Data suggest that about 9% of people with ET may develop MF within 10 years, and about 30% may develop MF after 20 years.

Acute myeloid leukemia (AML)
In a smaller number of people, ET can advance into AML, an aggressive type of blood cancer that grows quickly and results in too many immature white blood cells in the blood and bone marrow. AML often moves from the bone marrow into the blood and can sometimes spread to other parts of the body. About 1.5% of people with ET may develop AML within 10 years, rising to around 7.6% after 20 years.

Other potential ET complications

Enlarged spleen (splenomegaly)

In some people with ET, the spleen can become enlarged as part of the disease process. An enlarged spleen, or splenomegaly (splee-nuh-MEG-uh-lee), may:

- Cause a bloated or full feeling in the left side of the abdomen
- Make you feel full more quickly when eating

Bleeding and bruising

Some people with ET, especially those with very high platelet counts, may experience increased bleeding or bruising. This can happen when extremely elevated platelets interfere with normal clotting. You may notice:

- Easy or frequent bruising
- Nosebleeds
- Bleeding gums
- Heavier or longer menstrual periods
- Prolonged bleeding from minor cuts

Microvascular complications

ET can affect the small blood vessels (microvasculature), which may lead to symptoms that come and go or feel hard to explain. These symptoms are often related to changes in blood flow or platelet activity. You may experience:

- Headaches or migraines
- Dizziness or light-headedness
- Blurred vision or brief vision changes
- Burning, redness, or pain in the hands and feet (erythromelalgia)
- Sexual problems

Resources to help you take charge of ET. Scan the QR code or visit PieceTogetherET.com/resources to discover more self-advocacy tools and lifestyle tips to help you navigate your ET journey with confidence.

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US-ET-2600010 (v2.0) 03/2026