

ANEMIA, IRON DEFICIENCY & HHT



COMPANION FACTSHEET TO
MY HHT CARE CHECKLISTS

SIGNS AND SYMPTOMS

WEAKNESS AND FATIGUE
SHORTNESS OF BREATH
DECREASED EXERCISE TOLERANCE
LIGHTHEADEDNESS
POOR MEMORY OR DIFFICULTY
CONCENTRATING
FAST HEARTBEAT (PALPITATIONS)
LOW BLOOD PRESSURE
FAINTING
RESTLESS LEGS
POOR SLEEP

FACTSHEET
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SOME IMPORTANT FACTS TO REMEMBER ABOUT HHT ARE:

Approximately 50% of patients with HHT develop anemia.

Iron deficiency without anemia is important and should be treated.

Anemia is most common in adulthood and only rarely in childhood.

Anticoagulant and antiplatelet therapy is not absolutely contraindicated in HHT patients and individualized patient bleeding risks should be considered.



The Cornerstone of
the HHT Community

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HERE ARE SOME THINGS TO DISCUSS WITH YOUR PHYSICIAN:

If you have been previously diagnosed with and/or treated for anemia or iron deficiency.

If you have a medical condition for which anticoagulation is recommended.

If you have any of the listed signs and symptoms.

Blood work for anemia (complete blood count, iron panel and ferritin).

Additional testing you might need for other causes of anemia.

Whether referral to a hematologist is indicated.

Getting screening and/or treatment at a HHT Center of Excellence.

Anemia is a decrease in the number of **red blood cells (RBCs)** or hemoglobin in the blood. **Hemoglobin** is the compound that allows RBCs to carry oxygen throughout your body. Anemia leads to reduced oxygen flow to the body's organs.

Anemia is a common complication in people with **HHT (Hereditary Hemorrhagic Telangiectasia)**, occurring in approximately 50%, typically diagnosed in adulthood and only rarely in children with HHT. The primary cause of anemia is iron deficiency secondary to chronic mucocutaneous bleeding (nosebleeds and/or GI bleeding from telangiectasias). **Iron deficiency** by itself is also a common and important manifestation of HHT. Lack of iron makes it harder to produce RBCs, is associated with symptoms similar to anemia and makes anemia more likely to occur if active bleeding occurs as the body will not have the needed iron available to produce the lost RBCs.

Patients with HHT should be screened for iron deficiency and anemia, and then supported with **iron replacement** and red blood cell **transfusion** when indicated. Anticoagulation is not absolutely contraindicated in HHT patients. When there is an indication for **anticoagulant** or **antiplatelet therapy**, individualized patient bleeding risks should be considered.

HOW IT IS DIAGNOSED

- > **Complete blood count (CBC) and ferritin.**
- > **Iron panel** (serum iron, total binding capacity, and transferrin saturation).

TREATMENT

- > **Oral iron supplements:** This is the initial recommended therapy and should include a healthy diet that is rich in iron containing foods. It should be noted that it is unlikely that changes to diet will have a significant impact on those people who are significantly iron deficient.
- > **IV (intravenous) iron replacement:** Recommended for patients who do not respond, or can not tolerate, oral iron.
- > **Red blood cell (RBC) transfusions:** This should be utilized for patients who are **severely anemic** and who have other factors that increase their risk for complications related to their anemia (i.e. underlying **heart conditions**).

AFFILIATED ISSUES

- > GI bleeding
- > Nosebleeds



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