

# NOSEBLEEDS (*Epistaxis*) & HHT



COMPANION FACTSHEET TO  
MY HHT CARE CHECKLISTS

## SIGNS AND SYMPTOMS

NOSEBLEEDS

TASTING BLOOD IN BACK OF THROAT OR MOUTH

VOMITING BRIGHT RED OR BLACK FROM SWALLOWING BLOOD

ANEMIA (LOW BLOOD COUNT)

IRON DEFICIENCY (LOW AMOUNTS OF IRON IN BLOOD)

SIGNS AND SYMPTOMS OF ANEMIA AND IRON DEFICIENCY (*SEE ANEMIA AND ANTICOAGULATION FACTSHEET*)

FACTSHEET  
**FS**

## CONTACT US

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## SOME IMPORTANT FACTS TO REMEMBER ABOUT HHT ARE:

Nosebleeds occur in approximately 90% of adults with HHT.

Nosebleeds can significantly impact quality of life.

Nosebleeds often lead to iron deficiency and anemia.

Nosebleeds can be life-threatening if severe.

Moisturizing topical therapies are the initial mainstay of nosebleed care.

The expertise of an ENT doctor is often required to treat nosebleeds.



The Cornerstone of  
the HHT Community

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## HERE ARE SOME THINGS TO DISCUSS WITH YOUR PHYSICIAN:

Nosebleeds or any of the listed signs and symptoms that bother you and impact your quality of life.

Moisturizing topical therapies for my nose.

Treatment with tranexamic acid tablets.

Getting an HHT-experienced ENT doctor for ablative therapies.

Referral to a hematologist to discuss the use of bevacizumab if indicated.

Ask for packing that won't likely make your nose rebleed, such as liquid packing, dissolvable packing or lubricated low-pressure packing.

Blood work to evaluate for anemia and iron deficiency (complete blood count, ferritin levels, iron panel).

Getting an expert opinion from an HHT-experienced ENT doctor and/or at an HHT Center of Excellence.

**Nosebleeds (epistaxis)** are the most common sign of **HHT (Hereditary Hemorrhagic Telangiectasia)**, developing in 90% of adults with the disease, affecting quality of life and often leading to iron deficiency and anemia. Typically, turbulent nasal airflow with breathing leads to mucosal dryness and bleeding from telangiectasias of the nasal mucosa.

Topical moisturizing may help to prevent the telangiectasias from cracking and bleeding and is a initial mainstay of epistaxis care. When nosebleeds do not respond to moisturizing, other therapies are considered, including oral antifibrinolytics, ablative therapies, systemic antiangiogenic therapy and surgical management. The expertise of an ear, nose, and throat (ENT) doctor, also called an **otolaryngologist**, is often required for management of epistaxis.

### HOW IT IS DIAGNOSED

- > **Clinical history and physical examination.**
- > **Blood work** to evaluate for anemia and iron deficiency (complete blood count, ferritin levels, iron panel).

### AFFILIATED ISSUES

- > Anemia and iron deficiency

### TREATMENT

- > **Moisturizing topical therapies:** Topical moisturizers (spray or gel) are typically used during the day.
- > **Oral antifibrinolytics (tranexamic acid):** An oral medication that can be used for patients that do not respond to moisturizing topical therapies.
- > **Ablative therapies for nasal telangiectasias:** These are procedures performed by an **ENT** doctor for patients that do not respond to moisturizing topical therapies. Treatments include laser treatment, radiofrequency ablation, electrosurgery, and sclerotherapy.
- > **Nasal packing:** Can be used for epistaxis that is difficult to stop. Packing unlikely to make the nose rebleed should be used, such as **liquid packing**, **dissolvable packing** or **lubricated low-pressure packing**.
- > **Bevacizumab (Avastin):** A medication used to treat a number of types of cancer. Although not a chemotherapy drug, it slows the growth of blood vessels and has been shown to help reduce nosebleeds. Bevacizumab is available as a nasal injection or Intravenous (IV) treatment for HHT. There are potential side effects which should be considered prior to treatment.
- > **Septodermoplasty surgery and nasal closure surgery (Young's procedure):** Reserved for patients who have failed other treatments and should be discussed with an HHT-experienced **ENT** doctor.



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