

Do's and Don'ts Factsheets

for Rare Vascular
Disease Care in
Frequent Situations

*For
Patients*

Hereditary Hemorrhagic Telangiectasia

Epistaxis



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Introduction

This fact sheet has been prepared by the members of the VASCERN Hereditary Hemorrhagic Telangiectasia (HHT) Working Group to provide guidance on the proper management of epistaxis (nosebleeds). It is intended for patients and caregivers. Epistaxis can be a common occurrence, and knowing the correct steps can help manage the situation effectively and safely.

The HHT WG endorses these recommendations, but would like to emphasize that they have been made by consensus at the expert level. We recommend that you use this fact sheet as a guide and consult with your physician about your specific situation to ensure the most appropriate care for your individual needs.

Acute Epistaxis



WHAT IS RECOMMENDED

- Sit down in a calm and secluded space.
- Ensure that a sink or container (e.g., plastic bag) is nearby.
- Maintain your head in a straight position or tilt it slightly forward.
- Try to stop the bleeding by applying firm pressure (fingers or a nasal clip) to all soft tissues of your nose for a minimum of 10 minutes.
- Applying ice to the neck or the palate could reduce blood flow.



WHAT YOU SHOULD NOT DO

- Lay down or tilt your head back.
- Swallow your blood.
- Allow the blood to flow without trying to apply pressure to your nose.

Persistent Epistaxis After Compression



WHAT IS RECOMMENDED

- Apply self-packing.
- Discuss this in advance with your ENT specialist.
- Call for help.



WHAT YOU SHOULD NOT DO

- Lay down or tilt your head back.
- Swallow your blood.
- Allow the blood to flow without trying to apply pressure to your nose.

Preventive Measures



WHAT IS RECOMMENDED

- Apply ointment and/or nasal lubricants to the nasal cavity at least twice daily to prevent drying of the nasal mucosa.
- Avoid dry air, and if possible, humidify the surrounding air.
- Try gently rinsing your nose with a saline solution.



WHAT YOU SHOULD NOT DO

- Forcefully blowing your nose.
- Physically removing crusts from your nose.

Editorial Board/ Contributors

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VASCERN, the European Reference Network on Rare Multisystemic Vascular Diseases, is dedicated to gathering the best expertise in Europe in order to provide accessible cross-border healthcare to patients with rare vascular diseases (an estimated 1.3 million affected). These include arterial diseases (affecting the aorta to small arteries), arterio-venous anomalies, vascular malformations, and lymphatic diseases.

VASCERN currently comprises 48 expert teams from 39 highly specialized multidisciplinary HCPs? coming from 19 EU Member States, as well as various European Patient Organisations, and is coordinated in Paris, France.

Through our 6 Rare Disease Working Groups (RDWGs) as well as several thematic WGs and the ePAG – European Patient Advocacy Group, we aim to improve care, promote best practices and guidelines, reinforce research, empower patients, provide training for healthcare professionals and realize the full potential of European cooperation for specialised healthcare by exploiting the latest innovations in medical science and health technologies.

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