

# Nosebleed Self-Help

## *Suggestions from other Sufferers*

We've been listening. At the HHT Foundation and at HHT Centers, we hear daily cries for help with your nosebleeds. Also, we hear many suggestions and ideas about what seems to help.

Nosebleeds are a problem for almost everyone with HHT. For many they are manageable over a lifetime with just self-applied pressure to the side of the nose at the time of a nosebleed. But for others they can be the cause of anemia (low blood count) or can affect the quality of life. Those who fall into this latter category of course seek methods to stop or limit the nosebleeds in order to avoid the ENT's office or hospital emergency room as much as possible! We report here some products that are mostly available without prescription that patients have reported to be helpful.

The management and treatment of nosebleeds in HHT unfortunately has not been well studied. This is an area of clinical research that desperately needs randomized clinical trials comparing different approaches. This means that very little can be recommended to manage nosebleeds which has been studied in terms of its safety or effectiveness. Yet we understand that in the meantime, HHT patients are calling for help and suggestions.

"Less is more" is a good guiding principal in the management of HHT nosebleeds. Too much, too early or too aggressive treatment of nosebleeds can actually damage the nose and worsen the nosebleeds later in life. Since there is currently no permanent cure for the nosebleeds of HHT, the goal is to reduce the frequency and severity.

Most nosebleeds stop with simple pressure over the bleeding point. Since HHT is a disorder of the blood vessel, not the blood itself, most patients have

normal clotting in response to a nosebleed. The formation of a clot is nature's way to stop a nosebleed. If the bleeding spot is in the front part of the nose, it can often be stopped by applying pressure by pushing on the outside of the nose. In general, this is preferable to packing the nose with tissue or cotton. This is because when tissue or cotton is removed it often sticks to the newly formed clot and causes a "rebleed". Additionally, pieces of tissue might remain in the nose and be a source of bacteria and infection. If it is necessary to place something in your nose to stop the bleeding, it is best to use a product specifically formulated for this purpose. Several are listed below and others are available for use by physicians.

External pressure works only when the bleeding originates from the front part of the nose, and therefore is sometimes not enough. Patients and physicians alike have been frustrated for years at the lack of products available to patients to help manage their own nosebleeds in this situation. Some of the products listed below are not new, but several are only recently available to HHT patients. We focus mostly on those available without prescription, or that are widely prescribed by primary care doctors for patient use.

A general rule is that there is probably not a general rule. There is some trial and error involved with successful self-management of recurring nosebleeds and what works for one person might not work for someone else.

### Reducing Nosebleeds

#### **Ointments**

Most nosebleed sufferers as well as ENT doctors believe that keeping mucous membrane moist and lubricated helps reduce the frequency of nosebleeds. One sufferer summarized his tactic regarding this point by saying "You have to keep it really moist always. Better that ointment drips from the nose than blood".

Ointments are usually gently applied to the inside of the nose 3-5 times per day with the tip of the pinky finger or a q-tip.

**EXAMPLES:** Vaseline, KY-Jelly, Aquaphor, Bactriiban, paraffin cream

There is ongoing discussion among both patients and doctors about which type of ointment is best. Some recommend an ointment such as Bactriiban which contains some antibiotic. But some recommend against this- other than for a short time when there are signs or specific risks for infection. Some prefer a petroleum based ointment such as Vaseline because they tend to last longer than a water based ointment such as Aquaphor. Others prefer Aquaphor due to a potential small risk that a petroleum based ointment if inhaled into the lungs could cause lung inflammation.

#### **Home humidifier**

Most ENT doctors and many patients recommend this to help keep the inside lining of the nose from getting dry.

see **Nosebleed Self-Help**, page 10

# Nosebleed Self-Help, from page 9

## **Saline Nasal Sprays/Rinses**

Used to keep the mucous membrane of the nose moist and clean

**EXAMPLES:** Ary, Ocean Spray, Ponaris, NeilMed Sinus Rinse

## **Corticosteroid Nasal Sprays**

These are anti-inflammatory medications, and their primary use is to treat inflammation in the nose caused by allergies. In an HHT patient without allergies they are probably not helpful. In fact, one of their side effects is drying of the mucous membrane— in general something to avoid. When needed for treatment of nasal allergy symptoms, most come in an “AQ” (aqueous) form which helps decrease the drying side effect.

**EXAMPLES:** Beconase, Vancenase, Rhinocort, Nasarel, Flonase, Nasonex, Nasacort, Tri Nasal

## **Vitamins/Supplements/Foods**

None of these have been shown by studies to help, but each has been mentioned as helpful by multiple patients. In most cases there is at least “biologic plausibility” for them to be helpful and they are not known to be harmful in recommended amounts or doses.

- **Folic Acid/B vitamins**
- **Flavonoids**

**EXAMPLES:** Rutin, Soy

- **Genistein/Soy**—A number of patients have reported that taking genistein (a soy derived product) or eating soy has decreased their nosebleeds. One unpublished, small but randomized, double blind study showed a possible small decrease in the duration of nosebleeds in HHT patients receiving soy protein isolate (29 grams of SPI/40 mg genistein daily). However, the frequency and severity of nosebleeds was not shown to change in those taking soy. There has not been a study of the affect of soy on nosebleeds published in a medical journal to date.

- **Cod Liver Oil**—A number of patients have reported that taking it by mouth has been helpful. There has been no controlled or published study of the affects of Cod Liver Oil or similar fatty acids on nosebleeds.

## **Stopping a Nosebleed**

### **Hemostatic products**

These are products specially made to stop bleeding once it has begun. It is important for effectiveness and safety to follow directions on the package carefully with these products. However, in case of brisk arterial bleeding, the pressure of the flow may prevent the powder or sponge from remaining in place, and bleeding may continue.

Many of these products can be difficult to find in your local pharmacy, but often pharmacies are willing to special order a product if asked. Otherwise, most of these products/companies have websites from which you can order directly.

- **Gauze/Sponge Products**

These are over the counter, dissolvable packing products. They promote clot formation and then “gelify” for easy, non-sticky removal to minimize rebleeding.

**EXAMPLES:** NasalCEASE, Seal-On

- **Powder Products**

These products were originally developed for use in trauma cases—to help promote clotting and create an artificial “bandaide” on wounds caused by accidents. Some should clearly not be used inside the nose because they create an exothermic (heat causing) reaction which would irritate the nose. Some have been successfully tried by HHT patients and are made of substances that are not thought to be harmful to the lining of the nose.

**EXAMPLES:**

Nosebleed QR (sold OTC and specifically for nosebleeds)

TraumaDEX/Bleed-X (same product, different packaging, not marketed to public- only to/for physicians and emergency professionals)

Yunnan Paiyao—chinese “herb”, comes in powder form, applied with cotton swab to bleed. Although we have heard of several patients who report success in using this, it is a combination of many herbs that have not been tested for use in the nose. There are some reports that it can cause irritation even when used on the skin. Use, particularly repeated use, on the very sensitive mucous membrane of the nose might cause problems. It is probably safer to use one of the similar powder products above that has been specifically developed for use in the nose.

### **Decongestant Nasal Sprays**

(oxymetazoline or xylometazoline)

**EXAMPLES:** Afrin, Dristan, Duramist, Genasal, Neo-Synephrine, Vicks Sinex, Twice-A-Day, Otrivin

These nasal sprays act by constricting blood vessels which reduces blood flow to that area and can help a nosebleed stop once started. Occasional use to help stop a bad nosebleed is probably ok and even recommended by some ENTs. But ongoing use can actually make matters worse due to the “rebound” affect associated with this class of nasal sprays. “Rebound” refers to the fact that about 3 days after they are used, the swelling and congestion in the nose actually increases and can last for about a week. The risk for nosebleeds during this time may actually be increased. Prolonged use might even cause permanent damage to the mucosa.

### **Icepacks/Ice chips**

Ice packs or ice chips within the mouth or on the back of the neck have each been shown by at least one small study to decrease blood flow to the nasal mucosa. Although theoretically this could help slow a nosebleed- there is little evidence or consensus among HHT patients or doctors about whether this helps in practice.

## Blood pressure

Monitor, and control if needed to decrease “stress” on the abnormal blood vessels (telangiectasias).

## Stress

Many people are convinced that they have more nosebleeds during times of stress—both good stress such as the month they got married and bad stress such as the day they were fired. Acupuncture and biofeedback has been advocated by some patients to decrease stress and increase their sense of calm and well-being. There may be a relationship between stress, increased blood pressure and nosebleeds.

## Other general measures

Be prepared. Carry things with you which might be useful in case of nosebleed- in a handy container that you can open easily. Swallowing blood is not harmful, but too much can make you feel nauseous. Some sufferers carry a swimmer’s nose clamp to temporarily stop blood from running out of their nose, so they can have both hands free to access their supplies. Others carry a plastic Ziploc bag to catch the blood. Doctors and patients alike feel that it is important to maintain a sense of calm when a nosebleed begins. A state of panic may worsen a nosebleed, as well as decrease your ability to effectively manage the nosebleed.

## Things to avoid:

Any medication that interferes with normal clotting should be avoided or taken only if the risk of not taking the medication outweighs the risk of increasing the severity of nosebleeds in a specific patient’s situation. There is almost no medication that a patient with HHT should “never” take, but many that should not be taken if other reasonable alternatives exist for the problem at hand. Non Steroidal Anti-Inflammatory Drugs (NSAIDs), including aspirin, are probably the most common drugs that can interfere with normal clotting. Also, be careful when deciding to take a supplement or herb that it does not have “blood thinning” properties or interfere with normal coagulation of the blood.

Some patients have reported that eating foods containing salicylic or ascorbic acid increase their nosebleeds. While it is known that these substances can slightly decrease the coagulation properties of blood, the practical significance is not clear. Due to discrepant reports from patients and lack of good information, no general recommendation can be given about foods to be avoided.

## Things not covered:

We have purposely focused in this article on over the counter, readily available nosebleed management aids, rather than procedures and products that must be ordered and managed by a doctor. That is another article, for another issue.

This article also has not addressed the monitoring and management of anemia and iron levels. This is yet another whole issue. But bear in mind- some HHT patients will need iron therapy monitored by a doctor, no matter what techniques they and their ENT doctor have tried to manage their nosebleeds.

This article was possible because you have shared your experiences. If something important was left out in your opinion, we would be grateful if you would let us know.

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## EASY WAYS TO GIVE

• **BELONG!** Remember to renew your HHT Foundation membership each year. If you wish, you can arrange to have your credit card charged annually so you don’t have to bother with renewal notices and mailing checks.

### • SPREAD THE WORD!

- Gift memberships are a wonderful way to support the Foundation while keeping family members or health care providers informed.
- Share HHT Foundation materials, our 800 number, our website address, and our list of HHT Treatment Centers with family, physicians, dentists. Educate everybody you can reach!

• **DONATE!** Give whatever you can to support the Foundation’s overall mission of education, advocacy, patient support, and research towards a cure.

• **MAKE USE OF UNITED WAY, COMBINED FEDERAL CAMPAIGN, OR OTHER GIVING PROGRAMS!** If your workplace has a United Way campaign, think of the Foundation when you plan your giving. If you are in the U.S. military or a Federal employee, the CFC works just the same way. Use the Foundation’s CFC number to designate the HHT Foundation as the beneficiary of your payroll deduction program. CFC Number: 2694

• **SHOP AT IGIVE.COM!** Shop online via this charitable website and a percentage of each purchase can be forwarded on to the Foundation. There’s a link to IGive from our website at [www.hht.org](http://www.hht.org), or simply go to [www.igive.com](http://www.igive.com).

• **PURCHASE GREETING CARDS AT [WWW.MORETHANCARDS.COM](http://WWW.MORETHANCARDS.COM)!**

A percentage of the price of each card purchased is donated to the Foundation. Just click on the HHT logo under “Our Supported Foundations” and you’re on your way.

• **GIVE ON-LINE VIA ORGANIZATIONS LIKE [JUSTGIVE.ORG](http://JUSTGIVE.ORG) OR [AMERICAN EXPRESS!](http://AMERICAN EXPRESS!)**

([www.americanexpress.com/give](http://www.americanexpress.com/give)). You can easily donate to the Foundation via these websites; the American Express program even lets you use your Rewards Points to give!

• **GET INVOLVED!** Engage in local fundraising with the guidance of our Local Fundraising Coordinator, Lisa Bass (410-239-3229). Take part in the Write-On campaign, or organize a dinner, walk-a-thon, or other fundraising event.