

# Intermittent self-nasal packing for intractable epistaxis in a patient with Ehlers-Danlos syndrome

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## Abstract

Intractable epistaxis is a difficult problem to manage, particularly in a case complicated by Ehlers-Danlos syndrome. This is the first report describing intermittent self-packing of the nasal cavities at home to reduce hospital admissions and control symptoms. Some of the potential problems and complications are highlighted.

**Key words:** Ehlers-Danlos Syndrome; Epistaxis; Treatment; Self Administration

## Case report

A 36-year-old lady with recurrent epistaxis frequently presented to Bradford Royal Infirmary, department of ENT Surgery. She first presented to the department in 1979 aged 14, with epistaxis following a netball accident. She developed a large septal perforation and a septal button was inserted. This was complicated by excessive bleeding, despite normal coagulation and platelet count. In 1985, a diagnosis of type VI Ehlers-Danlos syndrome (EDS) was made on the basis of joint hypermobility, light blue sclera, skin laxity, cardiac defects and a bleeding tendency. She has been admitted over 60 times in the last 23 years, with recurrent epistaxis. She has undergone many surgical procedures including three arterial embolizations, sphenopalatine artery ligation, Young's procedure and reversal. She has also tried medical therapies, including steroids, antibiotics, fibrinogen drops, tranexamic acid, kaltostat dressing, and desmopressin (DDAVP). Each of these surgical and medical therapies has had a temporary effect but the epistaxis has subsequently recurred.

With very few treatment options left available, it was suggested that she might consider self-packing to reduce hospital admissions and to control the symptoms at home. A 'Rapid Rhino' balloon pack was felt to be the most appropriate pack in her case and she was instructed on how to insert a 5.5 cm balloon pack safely and effectively and was discharged with a supply of packs. She was readmitted on one further occasion, due to dislodgement of the septal button after a minor nasal injury. Since then, she has reported excellent control of symptoms with intermittent self-packing, on average every three days.

## Discussion

Comparisons to intermittent bladder catheterization, which has been well established for over 25 years, can be made in this case. It has transformed the lives of many patients, who may have been otherwise housebound. A motivated patient and an enthusiastic teacher are essential for success with appropriately trained medical staff teaching patients in hospital or at home. Literature is an

important aid, with illustrated diagrams showing the correct insertion technique, pointing out potential complications and who to contact for advice. It is essential that the correct patients are selected to learn the technique, whether it be self-catheterization or nasal packing.

'Rapid Rhino' balloon packs (Figure 1) have only been commercially available in the UK since October 2001 and there is very little published literature about them. The Packs consist of a PVC balloon, which is surrounded by a carboxy-methylated-cellulose (CMC) net. The packs work in two ways. The pressure from the inflated balloon has a tamponading effect and the CMC converts into a gel-like, haemostatic hydrocolloid. The haemostatic mechanism is similar to other known clotting agents such as ADP, thrombin and collagen. A German study<sup>2</sup> showed that life-threatening epistaxis was stopped in 13 (100 per cent) of patients with Gel-packs, and there was no re-bleeding on removal of packs, although the numbers in the study were very small.

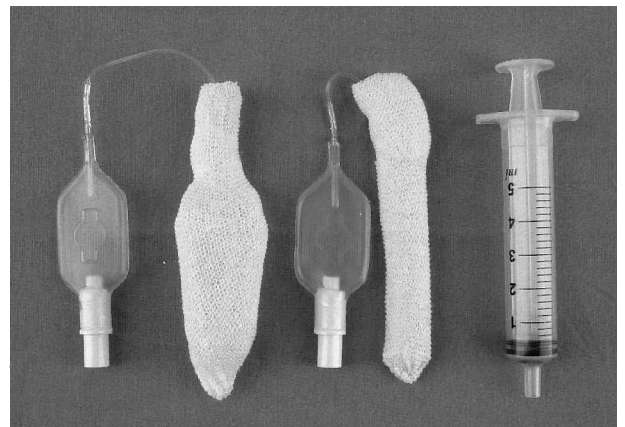


FIG. 1  
'Rapid Rhino' packs before and after inflation.

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The authors felt that that the 'Rapid Rhino' packs were the most appropriate in this case because they have a softer expansion than conventional packs and conform well to the abnormal anatomy of this patient's nose.

- **This is a case report of a patient with Ehlers-Danlos syndrome who has suffered recurrent epistaxis**
- **Conventional therapies had been tried and failed but she has now been successfully managed by self packing at home**
- **The authors comment upon the economics of this approach and compare its use to self-catheterization for urinary tract disease**

Initially the patient had to be instructed on how to safely insert the packs and be observed using them. The main points covered when instructing her were:

- (1) put the pack in horizontally along the floor of the nose (this was demonstrated with a diagram);
- (2) inflate the balloon with 10–15 ml of air, as tolerated;
- (3) do not force the pack if there is a lot of resistance;
- (4) use them for only three days at a time, before changing them;
- (5) if heavy bleeding persists around the packs, seek immediate medical advice.

The patient has had no complications from using the packs at home. She reported a great benefit from using the packs, particularly at night, but she also had greater freedom to move around the house during the day. Her main concern was inserting the pack incorrectly and pain associated with packing her own nose. However she found that she was proficient after two attempts and it has become less painful over time.

Complications of nasal packing are well recognized, such as further trauma and epistaxis, migration of the pack posteriorly, rhinosinusitis and in some cases toxic shock syndrome.<sup>3,4</sup> Also self-packing at home may mean that the patient does not seek medical help at the appropriate time. The potential benefits and risks of self-nasal packing must be considered in each individual case. Patients with epistaxis as a consequence of another disease process

such EDS, hereditary haemorrhagic telangiectasia or blood dyscrasias would almost certainly benefit from learning this technique.

The economic benefits of self-nasal packing cannot be ignored, the daily cost of a hospital stay being at least £200, and the average stay for epistaxis being 48–72 hours. By contrast a box of 10 'Rapid Rhino' packs cost £95, and last several weeks.

### Conclusion

Self-nasal packing is a viable option for carefully selected patients. It should be considered as another therapeutic option in this group of patients, who are often very difficult to manage effectively. Patients require adequate training and support for success. As urinary catheterization has transformed the practice of urology,<sup>1</sup> this technique can be used to improve the quality of life in those patients with difficult intractable epistaxis.

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