



# RHINOLOGY

Official Journal of the European and International Rhinologic Societies  
and of the Confederation of European ORL-HNS

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## *EPOS 4 patients*

*Claire Hopkins, Pavol Surda,  
Abigail Walker, Axel Wolf,  
Marlene M. Speth,  
Thomas Jacques  
et al.*

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Founded in 1963 by H.A.E. van Diehoek, *Rhinology* is a worldwide non-profit making journal. The journal publishes original papers on basic research as well as clinical studies in the major field of *rhinology*, including physiology, diagnostics, pathology, immunology, medical therapy and surgery of both the nose and paranasal sinuses. Review articles and short communications are also published, but no Case reports. All papers are peer-reviewed. Letters-to-the-editor provide a forum for comments on published papers, and are not subject to editorial revision except for correction of English language.

In-depth studies that are too long to be included into a regular issue can be published as a supplement. Supplements are in principle not subject to peer-review.

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# EPOS 4 patients



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## Conflict of Interest

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# Introduction

EPOS2020 is the 4th and most recent version of the European Position Paper on Rhinosinusitis and Nasal Polyps which was first published in 2005. It aims to provide the most up to date scientifically robust information on the topic published in the literature which has been critically analysed by an international group of clinicians drawn from all disciplines dealing with these problems together with patients. The guidelines offer evidence-based recommendations and care pathways for acute and chronic rhinosinusitis in both adults and children. Management of these diseases from the patients' perspective is an important part of EPOS2020. Not only is this included in the main document but, for the first time, we have produced a separate supplement dedicated to and in collaboration with patients, EPOS4Patients, which aims to provide information in an accessible format, to answer frequently asked questions about these diseases and their treatment options as well as including useful patient resources and websites.

It has never been more important for patients to be actively involved in their care. Being well informed helps you to make the best decisions together with your doctor.

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### 3. Acute Rhinosinusitis

#### What is it?

Acute rhinosinusitis (ARS) is a term that can be used to describe any short-lasting condition that causes inflammation of the lining of the nose and sinuses. However, most often when we use the term ARS it refers to an infection that causes the nose and sinuses to become swamped by cells that fight infection, which trigger inflammation as part of the effort to kill the agent causing infection. It is most often due to a viral infection, but occasionally can also be caused by bacteria. Symptoms of ARS include a blocked nose or a feeling of congestion, nasal discharge – either when blowing the nose or trickling down the back, green / yellow coloured mucus or even pus, or facial pain or pressure, headache, and reduction/loss of smell. When ARS is caused by an infection, it is often accompanied by the feeling of having a typical cold, with sore throats, cough, and fever being common alongside the problems in the sinuses.

#### What causes it?

ARS is very common and in fact is the thirteenth most common reason for patients to need to see a doctor. Adults have 2-5 colds per year, while school children have about 7-10 colds per year. Viral infections are much more common than bacterial infections and are thought to cause over 98% of all cases of ARS. However, cases that are more severe or long lasting may indicate a bacterial infection. The features that commonly help to indicate a bacterial infection include:

1. *How long symptoms have been present.*
  - A viral infection usually lasts less than 10 days, with the worst symptoms reached around 3-5 days. After this point, symptoms gradually get better and subsequently decline until resolution. Bacterial infections are more common when symptoms last longer
2. *"Double sickening"*

Table 3.1. Medications that may be used for viral causes of ARS.

	Reasons to consider this treatment	Reasons to not consider this treatment
Non steroidal anti-inflammatory drugs Ibuprofen	Relieves discomfort or pain	Caution in asthmatics, or those with stomach issues
Paracetamol (acetaminophen)	May relieve nasal obstruction and drainage	Do not exceed daily limits
Vitamin C	May have small benefit; has low cost and is safe	Poor quality evidence
Zinc	Zinc acetate or zinc gluconate lozenges at a dose of $\geq 75$ mg/day and taken within 24 hours of onset of symptoms significantly reduces the duration	May cause a bad taste and nausea
Echinacea		No evidence to support use
Herbal medicine: BNO1016 (Sinupret; extract of 5 herbal drugs), cineole (extract from eucalyptus oil with anti-inflammatory properties), andrographis paniculata SHA-10 extract	Sinupret can improve symptoms of a runny nose, postnasal drip, headache, facial pain; cineole can reduce symptom scores; Andrographis paniculata can reduce the prevalence and intensity of symptoms.	
Nasal irrigation with saline	Possibly has benefits for relieving symptoms of acute upper respiratory tract infections	
Decongestants	May relieve nasal obstruction and drainage	No consensus on effectiveness; no increase in adverse events
Steam/heated humidified air	May relieve nasal obstruction and drainage	No benefits or harms from use of heated, humidified air
Nasal corticosteroids	May relieve nasal obstruction and drainage but effect is small	Evidence does not support the use of nasal corticosteroids in most cases
Oral corticosteroids		Risks outweigh likely benefits
Homeopathy		No significant benefit
Antibiotics		Adverse effects, not recommended

- This term is used by doctors to describe when a patient initially seems to be recovering from their cold, but then suddenly gets worse again. This is a feature of bacterial infections.

### 3. Severe symptoms

- Bacterial ARS infections generally make patients feel more unwell than a typical cold and may result in severe facial pain located around one side, a high fever (>38°), mucus that looks green, yellow, or rusty brown; and signs of infection on blood tests if your doctor thinks these are required.

#### How is it treated?

Viral infections will virtually always get better with time, rest, and sticking to healthy behaviours such as staying well hydrated. There are some medications which are available over the counter that can help to relieve the symptoms while you are waiting to recover; these are listed in the table below. It is important that you always read the leaflets of any medications you take – even if bought over the counter – and that you tell your doctor about them before any new medicines are prescribed. Some branded cold remedies contain several drugs, such as paracetamol and decongestants, so check the contents before taking any additional medication to make sure that you don't exceed daily limits.

#### Treatments for the “common cold”/acute viral rhinosinusitis/ acute bacterial rhinosinusitis

If a doctor feels that a patient is likely to have a bacterial cause of their acute rhinosinusitis then it is likely that antibiotics will be the first line of treatment. Usually this is a short course of antibiotics targeted at the most common bacterial causes – and is quite different to the use of antibiotics in the longer lasting form of sinus disease, chronic rhinosinusitis. Antibiotics have a modest effect when used in patients with bacterial rhinosinusitis but are completely ineffective in viral infections. Their use can

occasionally have side effects such as rash, nausea, and diarrhoea. Additionally, there are some concerns that using antibiotics without proper consideration of whether a patient is suffering from a viral or a bacterial infection may lead to overuse, and in turn, allow bacteria to become resistant to current antibiotic treatments.

As well as antibiotics, bacterial rhinosinusitis symptoms can be made more tolerable by simple medications such as paracetamol.

#### Patient's experience

A 60-year-old female patient presented to an emergency department with headache, fever and purulent anterior nasal discharge. The patient was started on simple analgesia and was given advice to rest at home and told that if the facial pain would become one-sided and particularly severe, or if she noted a change in vision or eye swelling/reddening, then she would need to see a doctor immediately. However, within the next few days her fever settled and within a week all other symptoms also regressed without the need for further treatment.

#### When should I be worried?

Complications of ARS are very uncommon, but when they do occur they may be potentially life-threatening and patients who are concerned they may have a complication must seek medical attention immediately. Complications that may arise in ARS are illustrated in table 3. They may occur regardless of whether or not antibiotics have already been prescribed by your doctor.

#### Warning symptoms of complicated ARS requiring immediate medical care

- Swelling/redness surrounding the eyes
- Eye pushed down or out
- Double vision, new or suddenly worse visual impairment

Table 3.2. Medications that may be used for bacterial causes of ARS.

	Reasons to consider this treatment	Reasons to not consider this treatment
Pelargonium sidoides (P. sidoides)	Mean decrease in sinusitis severity	
BNO1016 (Sinupret)	Significant effect on nasal obstruction and mucous swelling	
Herbal compounds: Myrtol , herbal extract from essential oils	Significant improvement of total rhinosinusitis symptoms score	
Nasal corticosteroids	Only advised to prescribe a nasal corticosteroid when reduction of symptoms is considered necessary	
Saline irrigation and sprays		No evidence of benefit but low risk of harm
Oral corticosteroids		Risks outweigh likely benefits
Antibiotics	Can be effective in speeding up symptom resolution in patients whose doctor has made a diagnosis of a bacterial infection	Risks of side effects as described above

- Severe headache
- Reduced conscious level, or inability to respond when roused
- A tender lump / swelling on the forehead
- Neck stiffness

### **Recurrent ARS**

Recurrent acute rhinosinusitis refers to when an individual experiences four or more episodes in a single 12-month period. It is not quite as common as you might expect, and there are many conditions that can mimic rhinosinusitis such as migraine and tension type headaches. Additionally, recurrent ARS may actually be a sign of chronic rhinosinusitis and represent a flare up in symptoms on a background of chronic inflammation. If you think you are suffering from recurrent ARS that is interfering with your quality of life significantly, you should discuss your symptoms with your doctor.

### **Frequently asked questions**

#### **Why won't my GP give me antibiotics for my sinusitis as I need to get back to work quickly?**

*Antibiotics are powerful instruments to fight diseases caused by bacterial infections. Most cases of rhinosinusitis are caused by viral infections. Randomized, controlled trials did not show any benefits from the use of antibiotics in patients suffering from viral rhinosinusitis ('common cold'). On the other hand, antibiotics can cause several side effects that have to be considered. Only in the few cases of diagnosed, severe, acute bacterial rhinosinusitis or chronic rhinosinusitis, is the use of antibiotics indicated.*

#### **Is there anything I can do to help my acute sinusitis except take antibiotics?**

*Yes, several medications apart from antibiotics are available for the (symptomatic) treatment of acute rhinosinusitis. Treatment options comprise nasal saline irrigations, NSAIDs, paracetamol, decongestants, local steroids, etc. If you have any concerns they should be discussed with your doctor or pharmacist.*

#### **Is there anything I can do to reduce the risk of side effects from antibiotics?**

*The best way to avoid risks of antibiotics is to avoid unnecessary usage.*

*For the treatment of acute and chronic rhinosinusitis, a broad range*

*of medications apart from antibiotics are available. Treatment options comprise nasal saline irrigations, NSAIDs, paracetamol, decongestants, steroids, etc.. Treatment strategies should be optimized by consultation of your doctor or pharmacist.*

*Always follow the written instructions provided on how to take your medicines – some antibiotics should be taken with water (and no food or dairy products), while others should be taken with meals to reduce the risk of tummy upset and some react with alcohol. Take them at regular intervals if possible and complete the course prescribed. Some antibiotics react strongly with alcohol (especially metronidazole). There is some evidence that taking a probiotic can reduce the risk of antibiotic associated diarrhoea.*

*If you develop a rash, severe diarrhoea, vaginal itching or white spots on the tongue, please contact your doctor. If you develop any swelling of the lips or tongue, or difficulty breathing please seek emergency medical care.*

#### **When should I be worried about a sinus infection not settling down?**

*A viral sinus infection may be transitioning to a bacterial sinus infection when the sinus symptoms have lasted for longer than 10 days, there is severe local facial pain (usually one-sided), and/or a so called "double sickening" (when symptoms are improving and then suddenly worsen again) occurs.*

*Signs that a bacterial sinus infection may be becoming severe and require urgent medical attention include swelling/redness surrounding the eyes, change in vision (for example decreased, blurry or double vision), severe headache, sensitivity to light or sound, neck stiffness, confusion or change in consciousness. In these cases, one should consult a physician immediately.*

#### **I needed surgery for an abscess in my eye – could this have been prevented if I had antibiotics earlier?**

*No. Studies suggest early oral antibiotics do not prevent the development of complications. Although complications of sinusitis are rare, they often occur quickly, both in people who have and have not been given antibiotics*

## 4. Chronic rhinosinusitis without nasal polyps

### What are the sinuses?

The nasal cavity starts at the nostrils and travels backwards towards the throat. It is separated into left and right sides by a wall in the midline called the nasal septum. The sinuses are air filled spaces within the bones of the face that connect into the nasal cavity on both sides.

There are four groups of sinuses on each side: maxillary, frontal, sphenoid and ethmoid. The maxillary sinuses are large single cavities that occupy most of the space behind the bone of the cheeks. The frontal sinuses are behind the eyebrows and forehead. The sphenoid sinuses are at the very back of the nasal cavity, in the central part of the skull. The ethmoid sinuses are slightly different to the other sinuses – they occupy the space between the eyes, and have many smaller cells separated by very thin bone, like a honeycomb. We don't fully understand what role the sinuses evolved to do, and some people have missing or underdeveloped sinuses without developing any problems.

### What do the sinuses do?

The sinuses are coated by a continuation of the same lining of the nasal cavity. In a healthy person, they continuously produce a small amount of mucus, which travels naturally out of the sinuses and into the nasal cavity, where it eventually passes backwards into the throat by the movement of tiny hairs. This mucus helps to moisten the air that you breathe, and to trap and deal with any viruses and bacteria. These functions of the sinuses are thought to help protect the lungs.

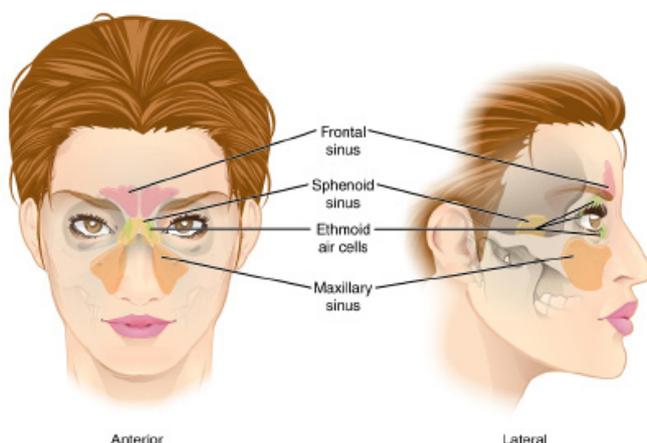


Figure 4.1. Diagram showing the position of the four sinus groups.

### What causes my sinus disease?

In some disease, patients can develop long lasting inflammation in the sinuses and nasal cavity. The most common of these conditions is chronic rhinosinusitis, where the lining of the entire nasal cavity and the sinuses becomes irritated and inflamed. Chronic rhinosinusitis is a disease with many causes. Understanding the background of disease is crucial so that we can offer a treatment that is likely to be effective.

### Chronic rhinosinusitis without nasal polyps

Chronic rhinosinusitis (CRS) can be divided into categories. Some kinds of CRS cause the patient to develop nasal polyps, and some kinds do not. Nasal polyps are inflamed swellings which fill the sinuses and nasal cavity.

As the name suggests, chronic rhinosinusitis without nasal polyps refers to the condition where the sinuses are continuously inflamed, but do not produce nasal polyps. The word “chronic” means that the condition affects patients in the long term (for at least 12 weeks, and often for years or decades) and does not have a “cure”. Luckily, it can usually be controlled with a combination of medical and surgical treatment.

### How is it diagnosed?

Patients with chronic rhinosinusitis without nasal polyps (CRSsNP) typically experience some or all of the nasal symptoms as indicated in Table 4.1.

In order to be diagnosed with CRSsNP, you have to be experiencing at least two of these symptoms over more than 12 weeks, and your symptoms must include blockage or discharge.

Table 4.1. Symptoms of chronic rhinosinusitis.

Symptom	Details
Nasal blockage/congestion	Usually on both sides. Nasal blockage is more common in CRSwNP but sinus congestion is found in both types
Nasal discharge (rhinorrhoea)	Often yellow or green, sometimes clear
Altered sense of smell	May be decreased, absent, or abnormal (for example an unpleasant smell in the nose). This is more common in CRSwNP but may occur in CRSsNP
Facial pain	Confined to the areas near the sinuses, usually not present all the time and usually changes in severity with other symptoms

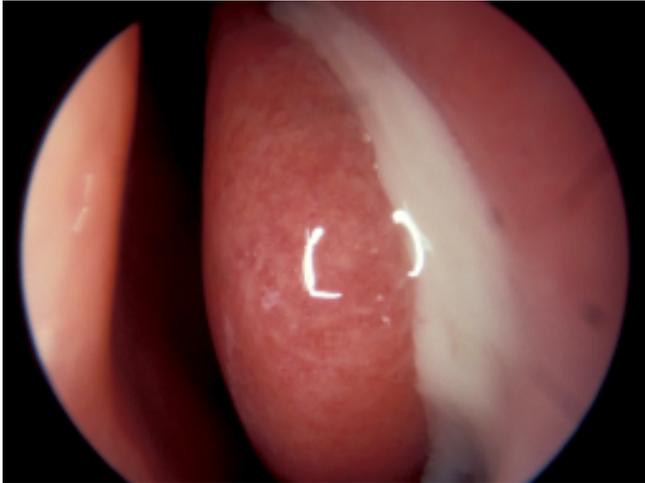


Figure 4.2. Mucopurulent secretions draining from the sinuses.

### How will a doctor know if I have this condition?

In addition to the symptoms it causes, CRSsNP is also diagnosed by a doctor examining inside the nose. Examining the nose with an endoscope (a thin telescope which is usually attached to a camera) allows the doctor to determine whether you have nasal polyps. It also allows them to see evidence of an inflamed nasal lining, or abnormal coloured mucus draining from the sinuses (Figure 4.2).

A doctor may also suggest organising a CT scan of sinuses – this is not essential for all patients, but it can be helpful if the diagnosis is in doubt or further treatment needs to be planned. In a patient without any sinus disease, the sinus spaces will appear black on a CT scan, as they are full of air. In a patient with CRSsNP, the sinuses may appear partially or completely full of mucus or swollen, inflamed sinus lining. This makes the sinus cavities appear grey rather than black on a CT scan. It is important to remember that having mucus or swelling visible on a CT scan does not mean that you have CRSsNP on its own: you must also be experiencing the characteristic symptoms.

ENT specialists may use specific medical questionnaires (known as “patient-reported outcome measures”) to assess the severity of CRS symptoms, and the impact of the disease on patients’ quality of life. The most common of these are the 22-question Sinonasal Outcome Test (SNOT-22), and visual analogue scales, where the patient is asked to rate the severity of each symptom on a scale from 1 to 10.

Blood tests are not essential for the diagnosis of CRSsNP.

However, some patients may have blood tests for the diagnosis of possible allergy (skin prick tests are another method of doing this), or to investigate possible immune deficiency or autoimmune diseases. Some patients have a swab of nasal secretions taken, in order to determine which kinds of bacteria are present; however, it is not clear how these results should be used to

Table 4.2. Possible causative factors related to CRSsNP.

Related factor	Details
Genetics	CRS is more likely if close family members have it. It is likely that many individual genes are involved.
Asthma	Strongly associated with all forms of CRS, including CRSsNP
Immune deficiency	May be tested for when CRSsNP is hard to treat
Viral infections	A viral infection can be the “trigger” for exacerbations of CRS
Bacteria	Presence of some bacteria is associated with severe CRS, but the relationship is complex.
Allergy	Not strongly associated with developing CRSsNP
Smoking	Smoking and passive smoking are strongly associated with CRS
Pollution	High pollution levels and some chemical exposures may be associated with CRSsNP

guide treatment.

### What causes CRSsNP

Our understanding of the different forms of chronic rhinosinusitis is improving constantly. However, we do not fully understand why some people develop CRSsNP and others do not. It is likely that each patient with CRSsNP will have a combination of several different factors, which come together to produce long-term inflammation inside the sinuses (Table 4.2).

It is important to remember that CRSsNP is not simply an “infection that won’t go away” – the truth is that the relationship between bacteria and CRS is much more complex, as many bacteria and fungi live in our sinuses, both in patients with and without sinus problems.

### 1. Medical treatments for CRSsNP

Once a patient is diagnosed with CRSsNP, they should be started on a long-term medication regime. For most patients, this will consist of:

#### **Saline (salt-water) nasal irrigation**

Regular saline nasal irrigation is a helpful and effective treatment for most patients with chronic rhinosinusitis. It improves symptoms by improving the flow of mucus, and potentially by washing away irritants and allergens in the nose. However, on its own, it does not decrease the inflammation that causes CRSsNP. Adding other ingredients such as Xylitol and sodium hyaluronate may have a positive effect in some patients, but patients should discuss this with their doctor first.

#### **Nasal steroid medication**

Nasal steroid medication is the main treatment used for most

patients with CRS. Steroids are medications that suppress inflammation, thereby reducing the patient's symptoms of blockage and discharge. The medication is known as "topical", meaning that it works by coming into direct contact with the inflamed lining of the nose and sinuses. Common steroids used include fluticasone, mometasone and budesonide. There is good-quality evidence that demonstrates that nasal steroids create a significant improvement in symptoms and quality of life in patients with CRS.

### **Other medications**

Some patients with CRSsNP do benefit from taking antibiotics, often for a longer period of time. However, we believe that this works by altering the immune system's response to the bacteria rather than by simply killing the bacteria directly. For further details on medical treatments, please refer to the appropriate leaflet.

## **2. Surgical treatments for CRSsNP**

Chronic rhinosinusitis is treated primarily with medical treatment (see above). The majority of patients will require long-term treatment with nasal steroid sprays/drops, saline irrigation and sometimes other medication. For some patients, this medication alone will be enough to control their symptoms. If a patient is already taking the maximum amount of medical treatment, but their symptoms are still affecting their quality of life, endoscopic sinus surgery (ESS) can be considered in order to give them better control of their disease. For further details, please read the patient leaflet titled "Surgery in CRS".

### **A patient report of living with CRS without nasal polyps**

*"At first I was told that I just had a simple 'sinus infection', but this has lasted for years. My nose produces a lot of yellow mucus, almost all the time. Occasionally my husband can smell it, which is so embarrassing. Quite often I can smell a really unpleasant smell that nobody else can. It puts me off my food. I find it difficult to breathe through my nose, which has affected my sleep and my energy levels throughout the day. It can be difficult to remember to take my nasal drops and the salt water irrigation; I just feel that I'm too young to be taking medication, even though they make me feel better."*

## **Frequently asked questions**

### **How common is rhinosinusitis?**

*The prevalence of chronic rhinosinusitis (symptoms lasting more than 12 weeks) is around 5%-10% in the general population.*

### **Are there any treatments I can get over the counter to help my sinus problems without having to see my doctor?**

*The availability of medications from pharmacies may depend on where you live, but your pharmacist is likely to be able to help and*

*is a great place to start. Saline nasal irrigation can be easily purchased from pharmacies and online, and steroid nasal sprays (such as fluticasone and mometasone) are also available without prescription in some countries. Both of these medications significantly improve the symptoms of sinus problems when taken regularly; they can take a few weeks to start working fully.*

*It is important to remember that nasal decongestant sprays (e.g. xylometazoline or oxymetazoline) improve your nasal airway quickly, but are not suitable for long term use, and can make your symptoms worse.*

### **Is CRS caused by allergies?**

*No, CRS is not usually caused by allergies. On the other hand, it can happen that patients with chronic rhinosinusitis also have allergies and the other way around. So, if you have chronic sinusitis and symptoms that raise the suspicion of an allergy like sneezing or itch, you can discuss an allergy test with your doctor.*

### **Should I stop smoking?**

*Yes. Stopping smoking is the single most effective thing you can do to improve your overall health and the length of your life. In terms of sinus disease, we know that smoking worsens the symptoms of chronic rhinosinusitis, and that stopping helps us to control your symptoms.*

### **I get terrible 'sinus headaches' but my ENT doctor has told me it is not coming from my sinuses? How can this be, as I feel the pressure in my forehead and between my eyes?**

*Many patients seek help from ENT specialists with headaches that they feel are coming from their sinuses. However, if headache and facial pressure are your main symptoms, it is unlikely that the cause is sinus disease. This is especially true if you do not have symptoms of nasal blockage or discharge. Your ENT may have examined your nasal cavity and found no evidence of sinus disease.*

*Long-term "tension-type" headaches can frequently be felt in the forehead, between the eyes and across the cheeks. We refer to this as "midfacial segment pain". When there is no evidence of sinus disease, this should be treated using similar medication as is used for other kinds of headache.*

### **So, does CRS ever cause headaches?**

*CRS can cause headaches but it is often not the most characteristic symptom of this disease. It is important to realize that headaches without symptoms like runny nose, blockage etc. are very unlikely to be caused by CRS. Headaches associated with CRS are often described as a heaviness or fullness and/or dull sensation. They are first noticed at the same time that other symptoms of CRS started and they usually fluctuate in severity along with other symptoms over time. They get better with successful treatment that improves*

other symptoms but may get worse with acute infections or when flying.

**My doctor asked me to add xylitol to my sinus rinse - how does this work?**

A number of different substances have been trialled as additives to saline rinse solutions, such as manuka honey, baby shampoo and xylitol. Of these, there is some evidence to support the use of xylitol, sodium hyaluronate and xyloglucan. It is thought that these likely improve the property of nasal mucus, and therefore help improve nasal function.

Please see also see the section on 'Nasal rinses' for more advice

**My doctor told me my sinusitis has come from my tooth - how can infection spread from my tooth to my sinuses, and how should it be treated?**

In some cases, inflammation and infection related to one of the upper molar (back) teeth can cause chronic rhinosinusitis on the same side. This occurs because the roots of the upper molar teeth are commonly within the floor of the maxillary sinus in your cheek. Patients usually experience congestion and an unpleasant-smelling discharge from one nostril. The affected tooth may be painful or not. This condition is known as odontogenic chronic rhinosinusitis. If you have sinusitis that is thought to originate from a tooth, the responsible tooth should be identified and treated by a dental professional. You may also benefit from treatment with antibiotics

and a steroid nasal medication, but the problem is unlikely to fully resolve unless the tooth is treated. If the responsible tooth cannot be identified, or the nasal symptoms continue after it has been treated, you may also benefit from having endoscopic sinus surgery to drain and widen the drainage pathway of the affected sinus.

**I'm always tired – is it caused by my sinus issues ?**

If you suffer from chronic rhinosinusitis, this can give rise to symptoms of tiredness, particularly if nasal blockage causes sleep disturbance, but there are many other causes of fatigue.

**What happens when I visit the ENT specialist? Do I have to have the camera and does endoscopy hurt?**

If you visit the ENT specialist with symptoms of your nose like runny noses or blockage of your nose, he or she will most likely have a look inside of your nose with both a speculum as with a camera (endoscopy). With the endoscope, it is possible to look a little bit deeper inside your nose than with the speculum. Nasal polyps arise a bit deeper/higher up in your nose and often they will not be seen if the doctor only takes a superficial look in your nose without the endoscope.

In general, endoscopy does not hurt. In rare cases, if it causes discomfort because your nose is too swollen or because of anatomic variations, local anaesthesia can be used in your nose. Local anaesthesia can for example be applied by placing cotton wools with anaesthetic inside of your nose, before the ENT specialist performs nasal endoscopy.

## 5. Chronic rhinosinusitis with nasal polyps

### What are the sinuses?

The nasal cavity starts at the nostrils and travels backwards towards the throat. It is separated into left and right sides by a wall in the midline called the nasal septum. The sinuses are spaces within the bones of the face that connect into the nasal cavity on both sides.

There are four groups of sinuses on each side: maxillary, frontal, sphenoid and ethmoid. The maxillary sinuses are large single cavities that occupy most of the space inside the bone of the cheeks. The frontal sinuses occupy part of the frontal bone, behind the eyebrows and forehead. The sphenoid sinuses are at the very back of the nasal cavity, in the central part of the skull. The ethmoid sinuses are slightly different to the other sinuses – they occupy the space between the eyes, and have many smaller cells separated by very thin bone, like a honeycomb. We don't fully understand what role the sinuses evolved to do, and some people have missing or underdeveloped sinuses without developing any problems.

### What do the sinuses do?

The sinuses are lined by the same tissue that lines the nasal cavity. In the normal situation, they continuously secrete a small amount of mucus, which travels naturally out of the sinuses and into the nasal cavity, where it eventually passes backwards into the throat. This mucus helps to keep the air that you breathe in moist, and also helps to trap and deal with any viruses and bacteria.

In some conditions, patients develop long-term inflammation in the sinuses and nasal cavity. The most common of these con-

ditions is chronic rhinosinusitis, where the lining of the entire nasal cavity and the sinuses becomes inflamed. Chronic rhinosinusitis is a disease with several different forms, caused by different kinds of inflammation.

### Chronic rhinosinusitis with nasal polyps (CRSwNP)

Chronic rhinosinusitis (CRS) can be divided into categories. Some kinds of CRS cause the patient to develop nasal polyps, and some kinds do not. Nasal polyps are benign inflamed swellings which fill the sinuses and nasal cavity, and sometimes require surgical removal.

As the name suggests, chronic rhinosinusitis with nasal polyps (or polyposis) refers to the condition where the sinuses and nasal cavity are continuously inflamed and produce nasal polyps. The word "chronic" means that the condition affects patients in the long term (for at least 12 weeks, and often for years or decades). This distinguishes it from "acute rhinosinusitis", which is a short-term illness that often results from a viral infection or common cold, but usually gets better within 2-3 weeks. CRSwNP is a long-term condition, caused by abnormal inflammation of the lining of the nose and the sinuses. It currently does not have a "cure", but it can usually be controlled with a combination of medical and surgical treatment.

### How is CRSwNP diagnosed?

Patients with chronic rhinosinusitis with nasal polyps (CRSwNP) experience some or all of the nasal symptoms described in table 5.1 over the long term.

In order to be diagnosed with CRSwNP, you have to be experiencing at least two of the symptoms over more than 12 weeks, and your symptoms must include blockage or discharge.

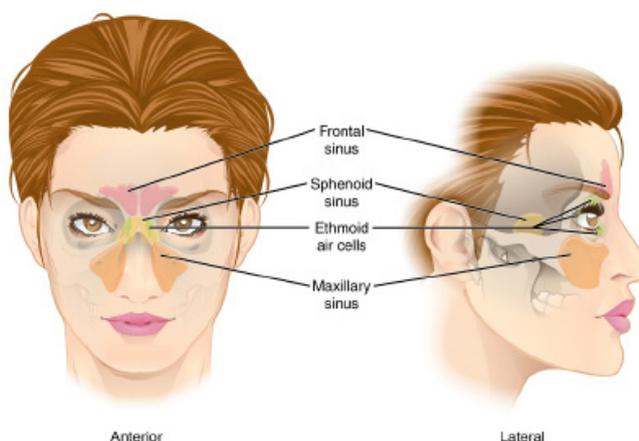


Figure 5.1. Diagram showing the position of the four sinus groups.

Table 5.1. Symptoms of chronic rhinosinusitis.

Symptom	Details
Nasal blockage/congestion	Usually on both sides. Nasal blockage is more common in CRSwNP but sinus congestion is found in both types
Nasal discharge (rhinorrhoea)	Often yellow or green, sometimes clear
Altered sense of smell	May be decreased, absent, or abnormal (for example an unpleasant smell in the nose). This is more common in CRSwNP
Facial pain	Confined to the areas near the sinuses, usually not present all the time, and less common in CRSwNP



Figure 5.2. Large nasal polyps visible in the left nostril.

In addition to the symptoms it causes, CRSwNP is also diagnosed by an ENT doctor examining inside the nose. Examining the nose with an endoscope (a thin fibre-optic camera) allows the ENT doctor to determine whether you have the form of the disease with or without nasal polyps. It also allows them to see evidence of an inflamed nasal lining, or abnormal coloured mucus draining from the sinuses.

The diagnosis of CRSwNP is also supported by performing a scan (usually a CT scan) of the nose and sinuses. It is not essential to have a scan to diagnose the condition, but it can be helpful if there is not enough evidence when the doctor examines you. It is also essential to have a scan if surgery is going to be performed. In a patient without any sinus disease, the sinus spaces will appear black on a CT scan, as they are full of air. In a patient with CRSwNP, the sinuses may appear partially or completely full of polyps or mucus with a swollen, inflamed sinus lining. This makes the sinus cavities appear grey rather than black on a CT scan. It is important to remember that having mucus or polyps visible on a CT scan does not mean that you have CRSwNP on its own: you must also be experiencing some of the symptoms in Table 5.1 above.

ENT specialists may use specific medical questionnaires (known as “patient-reported outcome measures”) to assess the severity of CRS symptoms, and the impact of the disease on patients’ quality of life. The most common of these are the 22-question Sinonasal Outcome Test (SNOT-22), and visual analogue scales, where the patient is asked to rate the severity of each symptom on a scale from 1 to 10.

#### **Blood tests are not essential for the diagnosis of CRSwNP**

However, some patients may have blood tests for the diagnosis of possible allergy (skin prick tests are another method of doing

Table 5.2. Possible causative factors related to CRSwNP.

Related factor	Details
Genetics	CRS is more likely if close family members have it. It is likely that many individual genes are involved.
Asthma	Strongly associated with all forms of CRS, especially CRSwNP.
Non-steroidal anti-inflammatory drug (NSAIDs) eg aspirin	In some patients with asthma and/or CRSwNP, symptoms are made worse by NSAIDs.
Immune deficiency	Should be tested for when CRSwNP is hard to treat.
Viral infections	A viral infection can be the “trigger” for exacerbations of CRS.
Bacteria	Presence of some bacteria (e.g. <i>Staphylococcus aureus</i> ) is associated with severe CRS, but the relationship is complex.
Fungi	Allergic fungal rhinosinusitis is associated with nasal polyps.
Allergy	Not strongly associated with developing CRSwNP.
Smoking	Smoking and passive smoking are strongly associated with CRS.
Pollution	High pollution levels and some chemical exposures may be associated with CRSwNP.
Systemic disease	Nasal polyps are common in patients with cystic fibrosis and eosinophilic granulomatosis with polyangiitis.

this), or to investigate possible immune deficiency or autoimmune diseases. Some patients have a swab of nasal secretions taken, in order to determine which kinds of bacteria are present; however, it is not clear how these results should be used to guide treatment.

#### **What causes CRSwNP?**

Our understanding of the different forms of chronic rhinosinusitis is improving constantly. However, for most patients, the exact cause, or “trigger” for developing CRSwNP is not clear, and we do not fully understand why some people develop CRSwNP and others do not. It is likely that each patient with CRSwNP will have a combination of several different factors, which come together to produce long-term inflammation inside the sinuses.

It is important to remember that CRSwNP is not simply an “infection that won’t go away” – the truth is that the relationship between bacteria and CRS is much more complex.

Many bacteria and fungi live in our sinuses, both in patients with and without sinus problems. Some bacteria (for example *Staphylococcus aureus*) may have a role in producing the inflammation in CRSwNP (due to special properties that these bacteria have). However, it is not the case that eradicating the bacteria in the sinuses with antibiotics usually cures the problem.

### Medical treatments for CRSwNP

Once a patient is diagnosed with CRSwNP, they should be started on a long-term medication regime. For most patients, this will consist of:

#### Saline (salt-water) nasal irrigation

Regular saline nasal irrigation is a helpful and effective treatment for most patients with chronic rhinosinusitis. It improves symptoms by improving the flow of mucus, and potentially by washing away irritants and allergens in the nose. However, on its own, it does not decrease the inflammation that causes CRSwNP.

#### Nasal steroid medication

Nasal steroid medication is the main treatment used for most patients with CRS. Steroids are medications that suppress inflammation, thereby reducing the patient's symptoms of blockage and discharge. In patients with more severe symptoms from their nasal polyps, steroid drops or steroid rinses are often used in place of sprays.

#### Other medications

In patients with severe symptoms, short courses (one to two weeks) of oral steroids (usually prednisolone) can be used to give a more rapid improvement in symptoms. This can help at the start of a course of nasal steroid spray or drops, to unblock the nose and give better access for the medications. Short courses of oral steroids can be given 1-2 times per year to enhance the control of CRSwNP. Oral steroids can be taken quite safely in the short term, but they are not generally continued in the longer term because of their side-effects.

New biologic treatments (monoclonal antibodies) have recently been approved in some countries for treating patients with very severe nasal polyposis, these medications block the inflammatory pathway and can reduce nasal polyp formation in some patients.

There are separate sections providing more information on all of these treatments.

### Surgical treatments for CRSwNP

Chronic rhinosinusitis is treated primarily with medical treatment (see above). The majority of patients will require long-term treatment with nasal steroid sprays/drops, saline irrigation and sometimes other medication. For some patients, this medication alone will be enough to control their symptoms. Where a patient is already taking the maximum amount of medical treatment, but their symptoms are still affecting their quality of life, endoscopic sinus surgery (ESS) can be considered in order to give them better control of their disease.

It is important to be aware that because CRSwNP is a chronic (long-term) condition, treatment does not cure the underlying

disease and polyps frequently return. Long-term medication is usually required in order to achieve disease control and patients may require surgery to be repeated.

### A patient's experience of living with CRSwNP

*I think the worst thing about it overall is if you don't keep on top of it can really get you down. In my job as a teacher I have to talk to students, and I sound like have a permanent cold and my words can be unclear it is uncomfortable and can be embarrassing. Fine food and wine used to be one of my greatest pleasures but now eating has just become a necessity as I am unable to smell and taste and no longer enjoy dining out in the same way. There is a safety aspect of not being able to smell as I can't smell if I am burning something in the kitchen. I can never leave the house without tissues, I've always got them, even in the summer I go through boxes of them.*

### What is "type 2" and "non-type 2" inflammation?

Chronic rhinosinusitis (CRS) is a complex disease without a single clear cause. Under the umbrella of CRS, there are different types of disease that likely respond differently to treatments and therefore the best treatment options may differ. For a long time, ENT surgeons have separated patients into two groups based on whether they have nasal polyps or not. Previous editions of EPOS used the same classification to help guide treatment choices, with different pathways for CRS with and CRS without nasal polyps.

However, over the past decade, our understanding of the processes that lead to CRS has significantly improved. We know that in all patients, certain parts of the immune system are over-active, leading to excessive inflammation in the sinuses, and the symptoms of CRS. Which exact part (or "pathway") of the immune system is over-active varies from patient to patient. In general, we can divide the kinds of inflammation that we see into "types" based on the immune cells and inflammatory mediators involved – the most common in CRS is Type 2, but there are also Type 1 and 3, and this will likely change further as our understanding evolves. We call these different endotypes; they can be thought of as a biological footprint and are probably the best predictor of how a disease will progress over time and how best to treat it. For this reason, EPOS 2020 separates patients into two groups – firstly, those with Type 2 inflammation, and then, secondly, all those with 'Non-Type 2' inflammation (ie Type 1 or 3).

Approximately 85% of patients with polyps have Type 2 inflammation, and between 10 -50% of patients without polyps. It is not straightforward to tell whether a patient has Type 1 or Type 2 inflammation, and doctors rely on markers in blood, tissue and other conditions – for example, we know that patients with severe nasal polyps (CRSwNP) and asthma are more likely to

have Type 2 inflammation. At present, a number of new medications (called biologics), which specifically target and reduce Type 2 inflammation are being investigated for their effects in CRS.

## Frequently asked questions

### How common is chronic rhinosinusitis?

*The prevalence of all types of chronic rhinosinusitis (symptoms lasting more than 12 weeks) is around 5%-10% in the general population; it is estimated that roughly 4% of adults have nasal polyps. They are more common in people with asthma.*

### Is CRSwNP caused by allergies?

*No, CRSwNP is not usually caused by allergies. On the other hand, it can happen that patients with chronic rhinosinusitis also have allergies and the other way around. So, if you have chronic rhinosinusitis and symptoms that rise the suspicion of an allergy like sneezing or itch, you can discuss an allergy test with your doctor.*

### Does CRSwNP cause headaches?

*CRS can cause headaches but it is often not the most characteristic symptom of this disease and is less commonly associated with CRSwNP. It is important to realise that headaches without symptoms like runny nose, blockage etc. are very unlikely to be caused by CRS. Headaches associated with CRS are often described as a heaviness or fullness and/or dull sensation. They are first noticed at the same time that other symptoms of CRS started and they usually fluctuate in severity along with other symptoms over time. They get better with successful treatment that improves other symptoms but may get worse with acute infections or when flying.*

### What's the difference between turbinates and polyps?

*Turbinates are normal anatomical structures in the nose that can be found in every human being. They consist of bone and the inner lining of the nose and play a role in humidification and heating of the inhaled air. Turbinates can be extra swollen for example in case of a viral upper airway infection or allergies.*

*Polyps are expressions of diseased mucosa of the nose and are not normal anatomical structures. They are benign growths that rise from the inner lining from the nose that typically will not go away on its own. They result in symptoms like runny nose, nasal blockage, decreased smell and sensations of fullness or heaviness.*

### I'm always tired – is it caused by my sinus issues?

*If you suffer from chronic rhinosinusitis, this can give rise to symptoms of tiredness, particularly if nasal blockage causes sleep disturbance, which is quite common in CRSwNP.*

### What happens when I visit the ENT specialist? Do I have to have the camera and does endoscopy hurt?

*If you visit the ENT specialist with symptoms of your nose like runny noses or blockage of your nose, he or she will most likely have a look inside of your nose with both a speculum as with a camera (endoscopy). With the endoscope, it is possible to look a little bit deeper inside your nose than with the speculum. Nasal polyps arise a bit deeper/higher up in your nose and often they will not be seen if the doctor only takes a superficial look in your nose without the endoscope.*

*In general, endoscopy does not hurt and polyps have no sensation. In the rare case it would be a bit painful because your nose is too swollen or because of anatomic variations, local anaesthesia can be used in your nose. Local anaesthesia can for example be applied by placing cotton wools with anaesthetic inside of your nose, before the ENT specialist will perform nasal endoscopy.*

### I don't want to keep using medication – it seems like we are just suppressing the symptoms instead of finding the cause. How can I cure this?

*Unfortunately, at present we do not have a cure for nasal polyps. Our treatments are aimed at reducing the symptoms caused by the nasal polyps; many patients may require long term intranasal corticosteroids to keep their symptoms under control, but these are safe to use and reduce the need for surgery or oral steroids.*

### How do I stop my polyps coming back after surgery?

*Using a regular maintenance intranasal corticosteroid after surgery will help to prevent nasal polyps coming back after surgery.*

### How do I know if I have Non-steroidal Exacerbated Respiratory Disease (also known as Aspirin Exacerbated Respiratory Disease or Samter's Triad)?

*The three main features of Non-steroidal Exacerbated Respiratory Disease (N-ERD) are asthma, chronic nasal polyps, and severe reactions to aspirin and other NSAIDs. Most patients with N-ERD also experience respiratory reactions to alcohol and an impaired sense of smell. Patients usually only develop symptoms in their 30's to 40's and they develop over a period of several years. The diagnosis of N-ERD is usually based on the medical history - only occasionally is an aspirin challenge is performed if the diagnosis is unclear.*

### What's the best treatment to improve my sense of smell?

*Your ENT surgeon can best advise you based on examination findings. Oral steroids, followed by nasal steroids can often improve and then maintain sense of smell. Unfortunately, in some cases, the sense of smell deteriorates after finishing the course and we wouldn't recommend more than two courses of oral steroids each year. Endoscopic sinus surgery or biologics would normally be considered in these cases and may further improve the sense of smell.*



**My ENT surgeon is suggesting surgery for my polyps but my allergist wants to put me on a biologic – what should I do?**

*Biological treatment is usually only recommended in patients with bilateral nasal polyps who have already had sinus surgery but who have recurrent polyps, or those who are not well enough to have an operation. Sinus surgery and good post-operative intranasal treatment can achieve long term disease control without the need for biologic therapies. However, if you have already had surgery but your polyps have come back, biologics are a good alternative. There are pros and cons to both approaches that you need to weigh up and there is no right or wrong answer. Ideally, it's best to have an*

*ENT surgeon and allergist who work together but this may sometimes be difficult. If they are suggesting different options ask them to explain why, and ultimately you will then need to make a choice based on the information provided and your own preferences.*

**Why am I not being offered a biologic for my nasal polyps?**

*Currently biologic therapies are not available for use in all countries. Where they are available, different criteria may be used to select patients. Generally, these criteria help to identify the patients who are most likely to benefit from biologics and those with more severe disease that is less likely to respond to other treatments.*

## 6. Rhinosinusitis in children and adolescents

### What is paediatric rhinosinusitis?

You may hear and read different terms in relation to your child's nasal symptoms. "Paediatric" refers to healthcare issues in childhood. "Rhinitis" is inflammation of the lining of the nose and can be caused in the short term by common infections, or over a longer period by an allergy. "Rhinosinusitis" is inflammation that affects not only the nose but also the sinuses. This can be chronic (lasting more than 12 weeks) or acute (less than 12 weeks).

What is the difference between acute and chronic rhinosinusitis?

Acute rhinosinusitis (ARS) is the sudden onset of two or more of the following symptoms;

- Nasal blockage/obstruction/congestion
- Or discoloured nasal discharge
- Or cough (daytime and night-time)

Strictly speaking, acute rhinosinusitis includes episodes of these symptoms that last up to 12 weeks; in reality most infections last only a few weeks and the majority settle down spontaneously.

Chronic rhinosinusitis (CRS) causes similar symptoms (listed below) but is present for 12 weeks or more:

- Two or more of the below symptoms, one of which should be either
  - Nasal blockage / obstruction / congestion
  - or nasal discharge (anterior/posterior nasal drip)

+/- facial pain/pressure;

+/-cough.

It can be more challenging to diagnose CRS in children, partly because they find it difficult to describe and communicate their symptoms. In addition, it can be hard to tell the difference between CRS and other common reasons for a blocked nose in children (such as allergic conditions, and enlarged adenoids). Your doctor will therefore take more information and examine your child to try to understand which condition your child has.

### Chronic rhinosinusitis (CRS)

#### How common is it?

It is difficult to say exactly how common chronic rhinosinusitis is in children but studies have shown between 2.1 to 4% of children may have symptoms associated with sinus disease. This makes it a less common problem than in adults, but there is undoubtedly a significant impact on the quality of life for children who suffer with CRS. The impact on overall health is greater than that of diseases such as asthma, attention deficit hyperac-

tivity disorder, juvenile rheumatoid arthritis, and epilepsy.

### What causes this?

The factors that lead to chronic rhinosinusitis in children are not fully understood. Overall, it seems most likely that rather than one single cause, it is due to a combination of several different factors that result in inflammation. These factors are not equally present in all children, and your child may only have some of the factors described below:

- Cigarette smoking (Passive smoking)
  - This is one thing that we do know contributes. One study showed that 68% of children with symptoms of acute rhinosinusitis were exposed to passive smoking, compared to a 1.2% among children without exposure
  - Studies have also demonstrated worse outcomes in children with CRS exposed to cigarette smoke. These include the need for more operations.
- Adenoids (a mound of immune tissue, similar to a tonsil that lies at the back of the nose) can contribute to CRS in children by harbouring bacteria and by causing blockage of the nasal airway.
- Although more clear evidence is needed there appear to be links to allergy, asthma and reflux disease.
- Rarely there are some conditions that can affect the nose and sinuses as well as the lungs such as cystic fibrosis that will require further investigation and treatment.

### What tests for CRS might a doctor offer for my child?

Depending on the information your doctor has as well as the examination findings there may be some further tests required.

These may include:

- Allergy testing (skin prick or blood tests)
- Scans of the nose and sinuses
- Assessment of the breathing/lungs
- Genetic testing

### What treatments for CRS might a doctor offer for my child?

The treatment of chronic rhinosinusitis in children is largely based on the therapies that have been found to be effective in adults. There is no good evidence in the literature to support the use of antibiotics for chronic rhinosinusitis in children.

The main medical treatments are;

- Nasal steroid medication
- Saline irrigation.

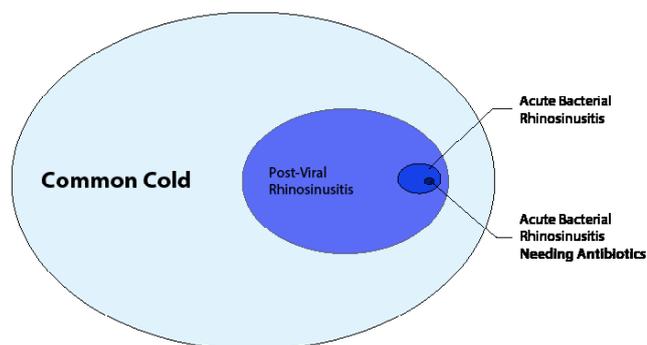


Figure 6.1. Depiction of relative frequency of cases of ARS that need antibiotics.

If nasal steroids are to be used, then your doctor will choose one which has as few side effects as possible and generally this is a very safe way to use medication. Often, they will ask to measure your child's height and weight regularly to make sure that the medication is not causing any problems.

Surgery can also be used to improve the control of symptoms in children, but usually this tends to be reserved for only the very few cases that do not respond to medications. A surgeon will usually choose the least invasive possible type of surgery for your child in order to balance the risks of surgery against improving the symptoms of disease.

### Nasal polyps

#### It is rare for children to develop nasal polyps.

Some children with allergic rhinitis may develop swollen turbinates (part of the internal lining of the nose) that may be mistaken for polyps. If your child does have nasal polyps these may just be caused by inflammation but it is likely that your doctor will request further tests to look for a cause. Cystic fibrosis, a relatively rare inherited disorder which affects the respiratory system is commonly associated with chronic rhinosinusitis with nasal polyps.

### Acute rhinosinusitis

Acute rhinosinusitis (ARS) as defined at the beginning of this leaflet covers a range of conditions from the common cold to bacterial rhinosinusitis with associated complications. What is important to understand is how rare symptoms of a blocked, runny nose will turn into anything other than the common cold.

It is believed that school children suffer from around 7-10 episodes of the common cold every year. Similarly to CRS, there is little in the way of scientific evidence to tell us who is more likely to get ARS. We do know that smoking and passive smoking increase the chances of developing ARS.

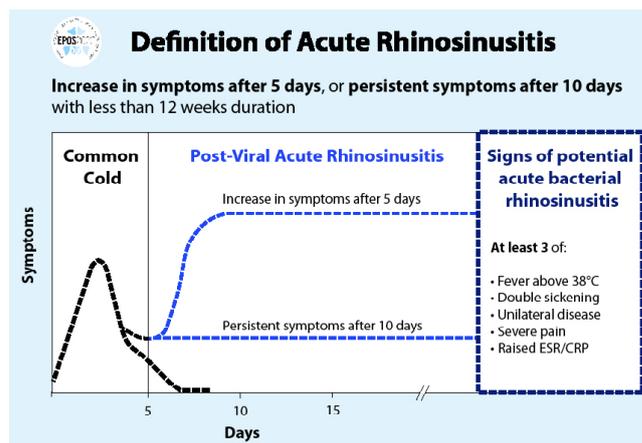


Figure 6.2. Typical timelines of the common cold and acute rhinosinusitis. CRP: C-reactive protein; ESR: erythrocyte sedimentation rate.

There are many different viruses that can cause the common cold some of these include:

- Rhinovirus
- Respiratory syncytial virus
- Influenza virus
- Adenovirus

The diagram below shows how the severity of the symptoms and the length of time assist us in making the diagnosis.

The common cold lasts typically 5-10 days but after 48 hours your child should experience a gradual improvement in symptoms. Post viral ARS either has symptoms lasting longer than 10 days or an increase in symptoms after 5 days.

Bacterial rhinosinusitis is rare but it is defined by the measures set out in the diagram such as a high temperature, severe pain, one sided symptoms, getting better then getting worse (double sickening) and abnormal blood tests.

### Can ARS make my child very unwell?

Complications of ARS are uncommon, but vital to identify and if you suspect any of these you should speak to a medical professional immediately. They most often occur early in the course of the illness, and some of the signs and symptoms to watch out for are:

- Swelling or redness around the eye
- Double vision
- Lethargy and confusion
- Severe headache or swelling over the forehead
- Rash, difficulty in bright lights or neck stiffness

Current evidence suggests that antibiotic treatment of ARS in general practice does not prevent complications.

### **Management of ARS**

One of the best ways to avoid the common cold is prevention. There is some evidence that probiotics and moderate intensity exercise can have an effect on preventing the common cold.

For the treatment of acute viral rhinosinusitis there is no evidence of benefit from antibiotics either for the common cold or for persisting acute purulent rhinitis in children. In fact, there is evidence that antibiotics cause significant adverse effects when given for the common cold.

Pain killers such as paracetamol and ibuprofen may help relieve some of the nasal symptoms as well as the systemic symptoms of pain and malaise. Your doctor may suggest saline rinsing and an intranasal steroid spray if your child's symptoms persist.

If a bacterial cause is suspected, it is important to watch out for the above signs of complications. The evidence for the use of antibiotics is poor but if you or your child are significantly unwell then you should seek further medical advice, and your GP may ask for the help of an ENT doctor at a hospital if your child develops signs of complications such as swelling around the eye or forehead.

## 7. Saline Irrigation (Salt water rinses)

### Why have you been prescribed this medication?

The goal of saline nasal irrigations is to improve symptoms and quality of life in chronic rhinosinusitis (CRS) patients with a low risk of side effects. Thus, saline irrigations represent one of the pillars of the treatment of CRS; however, their benefit in the treatment of post-viral or bacterial acute rhinosinusitis is less clear. Their proven benefit and their unlikely adverse effects make the saline irrigations a part of the first-line treatment for CRS patients, both in patients with CRS with nasal polyps and with CRS without nasal polyps. In addition, they have also shown their benefit in the case of children with CRS.

### How it works

Saline nasal irrigation may improve nasal function and therefore improve the symptoms. These irrigations help with the removal of crusts, mucus, and substances that stimulates inflammation of the nasal mucosa (allergens, biofilm ...) and improve the hydration of the nasal mucosa. Furthermore, they are also useful in the distribution of medications, such as intranasal corticosteroids, through the nasal cavity and paranasal sinuses.

### How, when and for how long you should use it

CRS as a chronic disorder usually requires a chronic treatment. Thus, saline nasal irrigations should be performed as the symptoms persist, or forever. There are many different methods for irrigations: nasal sprays, nasal squeeze bottles, nebulization, netipots, bulb syringes ... None has proven to be clearly better than another in improving symptoms. Thus, it is recommended to use the one with which the patient feels more comfortable. There are also high and low flow volume irrigations or hypertonic serum, though their benefit is not clear.

There is also no standard treatment protocol, but it is usually recommended to irrigate 1 or 2 times a day, before the application of the rest of the medication, such as intranasal corticosteroids.

Steroids are often added to salt-water solutions so that they can be rinsed into the sinus cavities, especially after surgery. There are many other substances that can be added to irrigations, however, the ones that have best shown benefit to the patient are xylitol, sodium hyaluronate, and xyloglucan.

In summary, saline nasal irrigations are recommended as the initial long-term treatment of CRS. You can perform it with various devices, using isotonic saline, once or twice a day, and prior to the application of the rest of your medication. In some cases, the addition of other substances may be useful.

Please see the linked video on the ERS website for a demonstration of saline irrigation.

Link to the video:

[https://1drv.ms/v/s!AoGcQbw7FUGNiNZQBjxp3w6pgaF\\_\\_g?e=9jp0aB](https://1drv.ms/v/s!AoGcQbw7FUGNiNZQBjxp3w6pgaF__g?e=9jp0aB)

### Side effects (and what to do if they occur)

One of the greatest advantages of saline nasal irrigations is that adverse effects are rare. Adverse effects such as local irritation, ear pain, nosebleeds, headache, nasal burning, and nasal drainage have been reported. The addition of substances to saline irrigations can favor the appearance of the mentioned adverse effects or others, as in the case of use of baby-shampoo and reversible smell loss.

If these side effects appear, changing the application device and reviewing the irrigation technique usually improves or solves them. In cases of persistence and worsening of symptoms, it may be necessary to stop.

### 2 patient reports on using the medication – tips, tricks, what to expect, etc.

Guillermo is a 38 year old male who was diagnosed a year ago with chronic rhinosinusitis with nasal polyps. He reported regular rhinorrhea and nasal congestion. At diagnosis, topical corticosteroids and nasal saline irrigations twice per day were prescribed. He declares that the symptoms improve a lot with the treatment and that even at times when some of the symptoms worsen, he performs irrigations more than twice a day. That helps him feel better. He performs high-flow irrigations (figure) with an isotonic solution on both sides. First, he flexes and turns his head and starts the irrigations through the upper nostril, making the irrigation come out through the other nostril. To irrigate the other side, change the position of the head to always wash from the upper side (video). This helps to clean nasal cavity and improve his symptoms of rhinorrhea and nasal congestion.

Patricia is a 45 year old female with chronic rhinosinusitis with nasal polyps, asthma, and intolerance to non-steroidal anti-inflammatory drugs (N-ERD: NSAID-exacerbated respiratory disease). She was diagnosed many years ago and has had two operations. She performs regular treatment with saline nasal irrigations 3-4 times a day and topical corticosteroids twice a day. She tells us that due to work reasons and lack of time, she stopped doing irrigations so regularly and she notices a significant worsening in her symptoms. She performs the irrigations

with a nasal spray with isotonic serum, two sprays on each side each time.

**Is it safe to use tap water?**

*Tap water isn't safe in many countries for use as nasal irrigation because it's not adequately filtered or treated. Tap water may contain microorganisms that could cause potentially serious infections. The best option is to use sterile saline, or when using tap water, it must be boiled and then cooled or passed through a filter.*

**How often do I need to clean or replace my saline irrigation bottle?**

*The irrigation bottle should be disinfected and cleaned to avoid infections. It is recommended to rinse the irrigation device with hot water and antibacterial soap and leave the device open to dry completely after each use. Besides, this device has to be periodically replaced. It is usually recommended to change it every three months according to the manufacturers' indications*

**I found an article about risk of infections with sinus rinse bottles – should I be worried?**

*There are some extremely rare, reported cases of severe infection after the use of nasal irrigations. However, these cases were associated with the use of non-sterile or non-boiled water, typically using well water, which is known to have a higher risk of amoebic contamination. Therefore, it is advisable to avoid the use of tap water and to carry out a correct and daily cleaning of the irrigation device.*

**Do I have to buy the salt sachets or can I make my own?**

*You can use salt sachets or you can buy a saline solution. If you prefer to do it yourself, it is recommended to use 2 teaspoons of both non-iodized salt and baking soda (sodium bicarbonate) for each litre of water. Remember that if the water used is not sterile it must be filtered or boiled to avoid infection. As a general guide, you should add ½ teaspoon of each for every cup (240ml, or one typical rinse bottle full of saline) of water. Some people prefer to mix and equal volume of salt and baking soda in an airtight container and add a teaspoon of the ready-made mixture to the rinse bottle.*

## 8. Intranasal corticosteroids (Nasal steroid sprays or drops)

### Why have you been prescribed this medication?

Your physician has prescribed this treatment because you have been diagnosed with chronic rhinosinusitis with or without nasal polyps.

Chronic rhinosinusitis (CRS) is an inflammatory disease of the nose and sinuses and intranasal corticosteroids (INCS) are the treatment of choice because they are demonstrated to have an anti-inflammatory effect. INCS might come as a nasal spray, nasal drops, or a solution to add to your nasal saline irrigation. Drops and solutions have higher dosage of corticosteroid medications than the nasal sprays. INCS can have a beneficial effect on all of your nasal symptoms including nasal blockage, excessive nasal secretions, and reduced smell. They have an excellent safety record and they can be used on a long-term basis.

### How it works

Intranasal corticosteroids have an anti-inflammatory action on the lining of the nose. Inflammation causes the nasal lining to become thickened and swollen; increases the number of cells that make mucus; and can lead to polyps being formed. Nasal steroids act to soothe the lining and reverse some of the effects of inflammation. The tissues become less swollen and there is a reduced production of nasal secretions. Your symptoms should start to improve and hopefully you will find that breathing through the nose becomes easier, your sense of smell may improve, and you have less troublesome nasal discharge. If present, they can reduce the size of nasal polyps with additional beneficial effects on nasal breathing, sinus blockage and sense of smell. These changes take time, as the body accommodates to the positive influence of steroids and gradually restores normal nasal function after months of inflammation. Therefore, nasal steroids may take quite some weeks or months before you notice their positive effects. However, most patients with CRS will notice that nasal steroids significantly improve their quality of life.

### How, when and for how long you should use it

It is important to use nasal steroids in exactly the way your doctor describes, and to use them every day at the prescribed dose. Before each dose, it is helpful to rinse with saline irrigation. This helps to clear mucus and debris from the nose that might block the uptake of the medication.

If you have been prescribed a spray, shake the bottle first and point your head slightly downward, looking at your feet, as

shown below. Apply one or two puffs in each nostril, as instructed, using your right hand for your left nostril and your left hand for your right nostril, while aiming the spray inside the nostril but slightly to the side - as if pointing it towards your ears. By using this technique, you can prevent the spray landing on the cartilage in the middle of the nose (the nasal septum) and reduce the risk of nosebleeds.

If you have been prescribed nasal drops, it is recommended to tip your head back in a 90° position as shown below to allow the drops to spread into the sinuses and the higher parts of the nostrils.

It is also possible that your doctor prescribed a corticosteroid that should be added to your daily nasal saline douching. This can be in the form of drops, powder, liquid or ointments. Your doctor will have explained the process of adding this medication to your wash bottle, and always make sure the medication is thoroughly mixed through the irrigation.

It is important to use your medication on a regular basis as directed by your doctor or pharmacist to gain the maximum benefit.

Using a nasal spray – head tilted forward, spray angled outwards towards ear, inhale the mist nice and gently (Figure 8.1).

Using nose drops – lie on the bed with your head tipped back-



Figure 8.1. Using a nasal spray – head tilted forward, spray angled outwards towards ear, inhale the mist nice and gently.

wards over the end of the bed (Figure 8.2).

### Side effects (and what to do if they occur)

Corticosteroid sprays do not have the same risks or effects as oral corticosteroids. This is because they have been specially engineered to target the lining of the nose only, and only a negligible amount is absorbed into the bloodstream.

Most side effects of nasal steroids are quite mild and related to the method of application. Dryness of the nasal lining with crusting and nosebleeds are the most frequently reported side effects. When this occurs, just check again the instructions given above on how to effectively use the spray using the opposite hand for each nostril. Sometimes, you may need to take a brief break from the medication to allow healing and then restart with the proper technique afterwards. If these side-effects recur, please let your doctor know as there are different spray applicators and types of steroids that can be used. Almost all patients find they can use nasal steroids with a minimum of side effects.

Adding corticosteroids to your nasal saline irrigations is a relatively new way of treating CRS and there is currently not a lot of data on the side-effects of long-term use of this treatment. However, it is likely they will be broadly the same as when steroids are used directly and not added to the wash bottle.

Several scientific studies have shown that nasal corticosteroid sprays and drops do not affect the pressure in your eye or cause cataract. But if you have pre-existing glaucoma – particularly a type of glaucoma called “closed angle” - you should mention this to your doctor before starting this treatment.

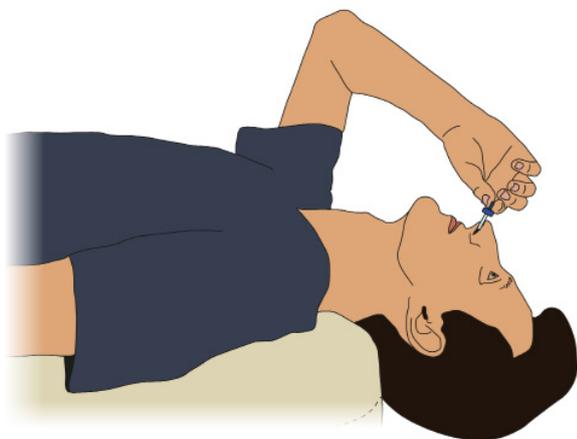


Figure 8.2. Using nose drops – lie on the bed with your head tipped backwards over the end of the bed.

### Patient's experience with intranasal corticosteroids

#### Patient 1 reports:

“Because of my problem of chronic rhinosinusitis, I use a nasal spray (INCS) that my doctor prescribed, daily; 2 puffs in each nostril. For me it reduces very effectively the amount of nasal secretions I had been producing. For many years, I had so many secretions at the back of my throat that I had the impression that air could not pass anymore/ to lack air. Since using INCS daily, I do not have this feeling anymore. When I forget the spray, for example on holiday, the postnasal drip recurs and reminds me to restart. When I have a cold, I double the dose to prevent it evolving into acute sinusitis. In general, I have more symptoms in winter and therefore I sometimes try to stop the INCS spray during summer.”

#### Patient 2 reports:

“I used to have a blocked nose, all year long, with regular exacerbations (headache and colored secretions) for which my GP prescribed oral steroids. Since I started using an INCS, I can breathe better through my nose, my sense of smell is better and I have no exacerbations anymore. The use of oral steroids could be heavily reduced. I still have episodes of increased secretions, but overall, I feel a lot better controlled than before.”

### Frequently asked questions

#### Why do my symptoms come back when I stop using the spray?

*Chronic rhinosinusitis is, as the name suggests, a chronic condition and up until now, no ‘cure’ is available to avoid the need for ongoing treatment. Good symptom control can usually be achieved by using a nasal spray in the long-term. Intranasal corticosteroids reduce the inflammation, but when you stop them, unfortunately, inflammation of the sinus mucosa will reappear and symptoms will recur.*

#### Is it safe to keep using nasal sprays as they have steroids in them?

*Yes, it is safe and it's even recommended/mandatory to use them for long(er) periods. Corticosteroid sprays (and drops) contain only a low dose corticosteroids and there is only very minor uptake into the bloodstream. They do not have the same side effects as oral corticosteroids. Most reported adverse events of INCS are mild in severity and related to the application method, such as minor bleeding. See the pictures above for the recommended application method.*

#### What should I do if I notice any blood in the mucus when I blow my nose?

*Mild nosebleed or blood in the mucus is the most frequent reported side effect of the use of intranasal corticosteroid spray and is in part related to the application method. (Be sure to spray in the direction*

*of the ears, away from the nasal midline/septum.) If this occurs, a brief break will allow the mucosal lining of the nasal septum to heal. You can just restart afterwards. In case of frequent recurrence, please inform your physician, who can prescribe a nasal ointment to smoothen and hydrate the nasal mucosa.*

**I've heard that steroids damage the lining if the nose – is**

**this true?**

*No. It can sometimes cause dryness of the nasal mucosa with crusting and mild nosebleeds as a consequence. When this occurs, a brief break will allow the mucosa of the nasal septum to heal and you can just restart afterwards. In case these side-effects reoccur on a regular base, please inform your physician, who can prescribe a nasal ointment to moisturise the nasal mucosa.*

## 9. Antibiotics in treatment of rhinosinusitis

### What are antibiotics used for in rhinosinusitis?

Antibiotics are medications to fight infections caused by bacteria. To cope with different kinds of bacteria, doctors have developed antibiotics that act in different ways – for example, some of them may fight bacteria through may damaging the wall or coating of the microbe, interfere with their ability to reproduce, or by blocking their growth mechanisms.

### The problem of too many antibiotics

However, bacteria can change and adapt to become “resistant” to antibiotics. This is because bacteria exist in populations of many millions, and amongst that enormous population there will be some that have a natural capability to defeat certain antibiotics. These bacteria will not only survive, but then will become parent bacteria for a whole new generation of bacteria that have the same natural capabilities to defeat antibiotics. This ability to evade or defeat antibiotics is what is meant by the term “resistance”.

Clearly, the problem of resistant bacteria poses problems for both healthcare professionals and patients as infections become harder to treat. However, we have also started to recognise that resistance is not the only problem caused by antibiotic use. Although some bacteria may cause infections, there are many millions of bacteria that live alongside humans without causing any problems at all. In fact, some of these bacteria are probably vital to keeping us healthy. This is the principle of the “probiotic” drinks that you might have seen in a supermarket. However, when we use antibiotics for an infection then some of these helpful bacteria will also be killed.

### Changing how we use antibiotics

For these reasons, there have been many changes to the way that doctors think about how to treat infections, and the best way to use antibiotics to avoid harm through their overuse. For instance, the routine use of antibiotics in acute rhinosinusitis (‘common cold’) in adults and children is not recommended because these are most often due to viruses (viruses are very tiny organisms that are entirely different to bacteria) On the other hand, antibiotics are powerful tools for treatment of infections caused by bacteria. Thus, careful assessment of what is thought to be the most likely cause of an infection is necessary.

### Acute bacterial rhinosinusitis

Although the most common cause of acute rhinosinusitis is a viral infection, in certain cases, it may be caused by bacterial

infection. This can be recognised by severe symptoms – e.g. fever above 38°C, feeling sick again after seeming to make an initial recovery, one sided disease, severe pain, or on rare occasions, signs that infection has spread out of the sinuses into the eye or brain (Table 9.1). Where these symptoms of a bacterial sinus infection are present, the use of antibiotics has some benefit, although are still not needed in most cases. The course tends to be short (<4 weeks) and uses antibiotics that target the most likely bacterial cause (such as amoxicillin / penicillin). Antibiotics in treatment of acute, bacterial rhinosinusitis are usually well-tolerated and improvement of symptoms can be expected within 10 days.

(For an example of the use of antibiotics for acute bacterial rhinosinusitis, see case report 1).

### Antibiotics for chronic rhinosinusitis

Chronic rhinosinusitis is a quite different disease to the short, sudden episode of infection described by the term acute bacterial rhinosinusitis. Acute infections can usually be linked to a virus or bacteria as the cause of the symptoms. By contrast, it is not nearly so clear what causes chronic rhinosinusitis and the role of bacteria in this differs from patient to patient.

Long-term antibiotics can be helpful in a certain subgroup of patients suffering from exacerbations of chronic rhinosinusitis with pus contained in their nasal discharge (or seen in the nose by a doctor with a nasal endoscope). In these cases, long-term courses of antibiotics (>4 weeks) can be prescribed in addition to baseline-therapy (i.e., nasal steroids and saline rinses). The antibiotics chosen are often of a type referred to as ‘macrolides’ and are used for their immunomodulatory effects. The aim of this treatment is to get through periods where symptoms may have ‘flared up’ and to be able to return to using the standard baseline-therapy of saline rinse and nasal steroids (see second patient experience).

In some cases, patients with chronic rhinosinusitis may develop

Table 9.1. Signs of acute, bacterial rhinosinusitis (≤3 of the following):

Fever above 38°C
Double-sickening
Unilateral disease
Severe pain
Raised inflammatory parameter

Table 9.2. Good antibiotic practise for patient.

Take medication exactly as described
Do not skip doses
Do not share with others
Do not save it for later
Report side-effects

an acute exacerbation, and in these cases, short courses of antibiotics may be used.

#### How, when and for how long you should take your antibiotics?

Antibiotics are usually prescribed as tablets, capsules or liquids. It is crucial to take medication exactly as your healthcare professional tells you (Table 9.2). Macrolides when used for CRS are usually given for up to 12 weeks in a low dosage and it can take at least 6-8 weeks before any improvement is noticed.

#### Side effects (and what to do if they occur)

Like all medications, antibiotics have side effects (Table 9.3): Gastrointestinal-related side effects (diarrhoea and loss of appetite) are reported frequently. Other side effects include rash, dizziness, nausea and yeast infections. The most serious side-effects include allergic reactions and *Clostridium difficile* infection causing diarrhoea, but these are rare. Macrolides also have a particular potential risk in patients with a background of heart disease (particularly used as long-term oral antibiotic treatment), and your doctor may ask you to undertake some

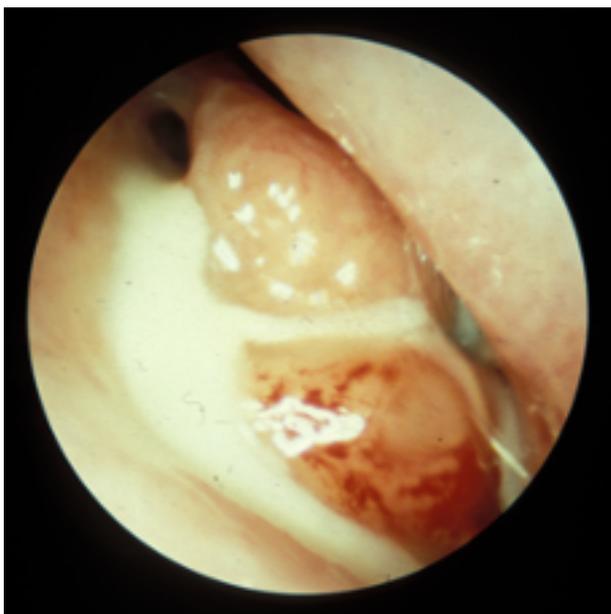


Figure 9.1. Purulent secretions diagnosed by nasal endoscopy.

Table 9.3. Common side effects of antibiotics.

Diarrhoea/anorexia
Rash
Dizziness
Nausea
Yeast infection
Allergic reaction

simple tests to check your heart health prior to starting this type of antibiotics.

#### Potential interactions

The use of antibiotics can be problematic in combination with other medications and in patients suffering from severe liver or kidney disease. Before taking any antibiotics, inform your healthcare professional regarding your personal medical history including allergies and other medication you may be taking to make sure that there is no interaction between this and the antibiotics. If side-effects do occur, there will be a leaflet contained within your medication that has information on whether these may be due to the medication. If you have any serious symptoms that you think are related to the antibiotics, please contact your healthcare team for further advice.

#### Patient's experience with antibiotic treatment

##### Patient 1 reports:

A 19-year-old female patient was presented to the otorhinolaryngologist suffering from fever (40°C), acute, severe, one sided facial pain and raised inflammatory parameters in the blood. Clinical examination including nasal endoscopy revealed purulent nasal secretion. Due to the combination of symptoms, a short-term course of systemic antibiotics was prescribed as add-on therapy to NSAID, saline sprays and decongestants. An improvement of symptoms was achieved after 3 days with total resolution after 1 week.

##### Patient 2 reports:

A 48-year-old male patient was presented to the otorhinolaryngologist suffering from chronic, bilateral, diffuse rhinosinusitis for more than 15 years. Since symptoms (nasal discharge and facial pain) increased 6 weeks ago, nasal steroids, saline rinses as well as a course of systemic steroids were prescribed. Unfortunately, symptom control was still insufficient. After additional workup including nasal endoscopy (showing purulent secretion), a course of long-term antibiotics was prescribed. Ten weeks after, a symptom relief was achieved, diagnostic nasal endoscopy showed no further purulent secretion and the patient returned to his baseline therapy including nasal steroids and saline irrigations.

## Frequently asked questions

### **Why won't my GP give me antibiotics for my sinusitis as I need to get back to work quickly?**

Antibiotics are powerful instruments to fight diseases caused by bacterial infections. Most cases of rhinosinusitis are caused by viral infections. Randomized, controlled trials did not show any benefits in the use of antibiotics in patients suffering from viral rhinosinusitis ('common cold'). On the other hand, antibiotics can cause several side effects that have to be considered. Only in the few cases of diagnosed, severe, bacterial sinusitis or chronic rhinosinusitis, the use of antibiotics can be indicated.

### **Is there anything I can do to help my acute sinusitis except take antibiotics?**

Yes, several medications apart from antibiotics are available for the (symptomatic) treatment of acute sinusitis. Treatment options comprise nasal saline irrigations, NSAIDs, paracetamol, decongestants, local steroids, etc.. Treatment strategies should be indicated according to the recommendation of your healthcare worker.

### **How can do long term courses work in chronic rhinosinusitis if it's not caused by infection?**

The mucus transport of the upper and lower respiratory tract ('mucociliary clearance') is the first line of defence in our respiratory system. Failure of mucociliary clearance can be caused by chronic or recurrent infections and can be improved by prolonged antibiotics in a certain group of patients.

### **Is there anything I can do to reduce the risk of side effects from antibiotics?**

The best way to avoid risks of antibiotics is to avoid unnecessary usage.

For the treatment of acute and chronic rhinosinusitis, a broad range of medications apart from antibiotics are available. Treatment options comprise nasal saline irrigations, NSAIDs, paracetamol, decongestants, steroids, etc. If you have any concerns you should discuss your treatment options with your doctor or pharmacist.

Always follow the instructions on how to take your medicines – some antibiotics should be taken with water (as some, like doxycy-

cline should not be taken with dairy products), while others should be taken with meals to reduce the risk of tummy upset. Take them at regular intervals if possible and complete the course prescribed. Some antibiotics react strongly with alcohol (especially metronidazole). There is some evidence that taking a probiotic can reduce the risk of antibiotic associated diarrhoea.

If you develop a rash, severe diarrhoea, vaginal itching or white spots on the tongue, please contact your doctor. If you develop any swelling of the lips or tongue, or difficulty breathing please seek emergency medical care.

### **When should I be worried about a sinus infection not settling down?**

A viral sinus infection may be transitioning to a bacterial sinus infection when the sinusitis symptoms have lasted for longer than 10 days, there is severe local facial pain (usually one-sided), and/or a so called "double sickening" (when symptoms are improving and then suddenly worsen again) occurs.

Signs that a bacterial sinus infection may be becoming severe and require urgent medical attention include swelling/redness surrounding the eyes, change in vision (for example decreased, blurry or double vision), severe headache, sensitivity to light or sound, neck stiffness, confusion or change in consciousness. In these cases, one should consult a physician immediately.

### **I needed surgery for an abscess in my eye – could this have been prevented if I had antibiotics earlier?**

No. Studies suggest early oral antibiotics do not prevent the development of complications. Although complications of sinusitis are rare, they often occur quickly, both in people who have and have not been given antibiotics.

### **Have I got CRS because my doctor didn't give me antibiotics at the beginning?**

No, this is unlikely to be the case. CRS is an inflammatory disease, not an infectious (for example, bacterial) disease. The underlying causes of CRS are not yet totally clear but because it is not infectious in nature, it is not thought to arise from untreated infectious disease, such as a bacterial rhinosinusitis.

# 10. Corticosteroids

## What are corticosteroids?

Corticosteroids are hormones that are naturally produced in the body. They play an important role in the everyday processes in your body like growth, repair, and responding to stress. Corticosteroids can be given as medication by using a man-made version of these naturally occurring hormones and may be given to patients for many different conditions. They may be given as tablets (“oral”), injection into the bloodstream (“intravenous”), or by sprays and creams (“topical”).

## Why you have been prescribed this medication?

Your physician has prescribed this treatment because you either suffer from a severe type of rhinosinusitis that does not respond well to other therapies or because you will undergo sinus surgery.

Chronic rhinosinusitis is an inflammatory disease of the nose and sinuses and steroids are amongst the most effective anti-inflammatory drugs available. In case of failure of other drugs such as nasal sprays, drops and rinsing, oral steroids can sometimes be used to bring you added relief. This is particularly true if you suffer from nasal polyps and if you suffer from smell problems or severe nasal obstruction.

In some cases where you are due to undergo sinus surgery with your doctor, corticosteroids may be used in the immediate few days prior to your operation as the reducing inflammation in your sinuses can help the operation be more straightforward, although this is not needed in most cases.

## How it works

Oral steroids have a strong action in reducing inflammation. They reduce swelling and the fluid that accumulates in unhealthy tissue and can help to soothe the vicious cycle of inflammation that can sometimes occur when the immune system is activated incorrectly. Through this action, they can reduce the size of your nasal polyps (if present) and improve your nasal breathing and sense of smell within days. Unfortunately, this change is not permanent and some patients will experience a relapse of some symptoms after steroid treatment has ended.

## How, when and for how long you should use it.

The tablet form of corticosteroids that are given to you by your doctor will come with a written prescription of how many tablets you should take, and how long you should take them for. It is important that you follow the treatment scheme exactly as prescribed by your physician. It is recommended to take the tablet(s) in the morning during breakfast.

Your treatment consists of tablets that, in some people needs to be reduced slowly over a certain number of days, usually only after long-term courses. This is because corticosteroids tablets can reduce the need to produce your own naturally occurring hormone levels; when the course of tablets is due to end then you may need to give your body a chance to start producing its own corticosteroids again. This slow reduction in tablet dosing is called a “taper” and if it is required, will be clearly written on your prescription. It is usually unnecessary after a short course.

## Side effects (and what to do if they occur)

Steroid hormones are active in almost every part of the body, and equally, their potential side-effects can be found in almost every part of the body. However, they do not occur in all patients and some people will be more bothered by them than others. Because of the potential harmful side-effects of the steroids, your physician will aim to strike a balance by prescribing you the shortest course possible that will still have a beneficial effect on your disease. The duration of this course can alter according to the type of rhinosinusitis you suffer from.

Steroid hormones have a stimulating effect on your body, with possible side-effects of agitation, palpitations and trouble falling asleep. For this reason, it is recommended to take steroid tablets in the morning so the effect will have faded by the time you have to go to bed. One of the most common side-effects of a short course of oral steroids is stomach upset, and some patients suffer heartburn or a feeling of acid reflux. Therefore, it is recommended to take your medication together with breakfast. If you have a history of stomach problems, your physician may prescribe an additional treatment to protect your stomach.

Oral steroids increase blood sugar levels and if you are diabetic, you must take extra care to monitor your blood sugar more closely than normal whilst you take oral corticosteroids.

These tablets also have an effect on your mood and you should inform your physician if you have any current or previous mental health problems. Some patients report that their mood can be altered during the time they take steroids, with some feeling high or excited and others feeling flat and depressed. If you suffer these extremes of mood, please do make sure you talk to your doctor about whether you should continue taking this medication.

More rare side effects include problems with the blood supply

to bones and heart problems.

If you have a history of diabetes, high blood pressure, heart disease, psychiatric disease, stomach problems or insomnia you should mention this to your physician before starting this therapy. Equally, if you have concerns about the risks of side effects then please talk to your doctor who will be able to offer information that is specific to your own personal health history.

In case you feel you react badly to the treatment, do not stop it abruptly, but contact your physician instead to discuss whether a change in dose or early stopping is indicated.

Because of its positive effects on growth and metabolism, oral steroids are considered doping by the World Anti-Doping Association (WADA) and if you are a competitive athlete, you should inform your sports physician about this.

### Potential interactions

Oral steroids can interact with other medications you may be taking and increase the risk of side effects of those drugs. You should let your doctor know about any medications you are taking prior to starting oral corticosteroids. If one or more of the medicines described below are prescribed to take at the same time as oral corticosteroids, your doctor may change the dose or how often you use one or both of the medicines:

- Increased risk of tendon rupture when taken with antibiotics of the quinolone family.
- Increased risk of stomach ulcers when taken with anti-inflammatory drugs of the non-steroidal family (NSAIDs, e.g. Ibuprofen, Naproxen, Diclofenac)
- Increased effect of certain drugs that thin the blood (warfarin) when steroids are taken in high dosages.
- Difficulties of regulating the blood sugar levels with certain anti-diabetes medication.
- Increased risk of low potassium levels in the blood when taken with drugs that interfere with the potassium levels such as certain diuretics or 'water pills' (e.g. Furosemide).

Always read the leaflet that comes with any other medication you take to check for any other rare interactions.

### Patient's experience with oral steroids

#### Patient 1 reports:

"Because of my problem of chronic sinusitis, I use a nasal spray that my doctor prescribed, on a daily base. Despite this treatment, every year (mostly during winter) I suffer from an acute sinusitis. My main complaints are headache, a blocked nose, secretions dripping down my throat and blocked ears with hearing loss. As a treatment, I always start with a nasal decongestant (never more than 1 week) and daily nasal saline washings.

However often, it takes 3 to 4 weeks for these symptoms to resolve. When they do not resolve by themselves, I ask my doctor to prescribe a course of oral corticosteroids like Medrol (especially when the hearing loss is annoying me). I take it for 12 days in a tapering dose: 4 days 16 mg a day, 4 days 8 mg a day, 4 days 4 mg a day. I take them in the morning, after my breakfast. Mostly, but not always, I start to notice a difference after 2 to 3 days. Besides the very bitter taste of the tablets, side effects that bother me, are a slightly nervous feeling and difficulties to fall asleep."

#### Patient 2 reports:

"Suffering from a chronic rhinosinusitis with nasal polyps for 8 years, was prescribed several courses of oral corticosteroids in my life to relieve the pain caused by this disease. It is true that my first steroid treatment relieved the feeling of obstruction, allowed my sense of smell to reappear and helped me sleep better over a period of 3 months. However, the symptoms subsequently reappeared. I could see that each new course of oral steroids relieved me over a shorter and shorter period. Therefore, taking Medrol today is less worth the effort than in the past. In addition, my last Medrol cure also had a significant impact on my morale, generating frequent changes in emotions."

### Frequently asked questions

#### Do oral steroids make you put on weight?

*One of the best-known side-effects of oral steroids among the general public and often the most feared one by patients is weight gain. It is true that the long-term use of oral steroids is linked to increased body weight when patients are taking this medication for several months to years, depending on the dose they receive, partly as steroids can increase the appetite. However, no weight gain has been shown with treatments shorter than 8 weeks, which is usually the case when treating rhinosinusitis. Some patients on short courses may report temporary water retention which will settle soon after the course has been completed.*

#### How many courses can you have in a year without risks of side effects?

*Oral steroids can have both early and late side effects. The early side effects, such as agitation, palpitation, insomnia and stomach disturbances can occur during an initial course. Others, such as diabetes, osteoporosis or cataract, occur only after several or long-term courses. There is not much known about how many courses will induce these long-term side effects and it will mostly dependent on your age, the dose of the steroids prescribed and other underlying diseases that you might suffer from. One study suggests that more than 2.5 courses per year (for any disease) should be avoided, and that the total life-time dose should also be carefully considered.*

**Isn't it safer to have steroids rather than surgery?**

*This is a difficult question that is not so easy to answer.*

*As mentioned before, long-term side effects of oral steroids can be serious and it will be difficult to predict who will develop these side effects and after how many courses.*

*Sinus surgery is also linked to certain complications that may depend on the extent of your disease as well as the type of surgery that is planned. But when surgery is performed by an experienced surgeon using appropriate equipment, serious surgical complications are very rare and manageable.*

*Therefore, it is accepted that sinus surgery is indicated for those patients at risk for developing steroid side effects, those that are not responsive to oral steroids or in whom multiple courses are needed to control their disease. One study suggests that in patients*

*requiring more than 2 courses per year, the risks versus benefits shift towards surgery being the better option.*

**Do oral steroids make me more likely to get sinus infections?**

*Several studies have shown that the use of long-term or high dose oral steroids (more than 700mg total dose) can increase the general risk of infection, because of their effect on the immune system. Also, asthma patients that take a substantial dose of oral steroids, have an increased risk of developing pneumonia. Although not properly studied, studies on short-term courses of oral steroids do not show an increased risk of developing acute sinus infections. So far, nothing is known about the use of long-term oral steroids and the risk of sinus infections.*

# 11. Biologics

## **Why you have been prescribed this medication?**

“Biologics” are medications that have been specially engineered to block the body’s pathways that generate inflammation. Biologics can be tailored to target the exact path of inflammation for different diseases and so have been used in many different conditions – for example, they have been used for some time in rheumatoid arthritis and psoriasis. In addition, there are now biologics that can target the airway and in particular can be used for the treatment of asthma and chronic rhinosinusitis (CRS), especially in those with nasal polyps (CRSwNP).

CRS is an inflammatory disease. It is usually treated using medications such as intranasal steroids and saline irrigation. Usually, these treatments are successful in controlling the disease. However, despite appropriate medical treatment, CRS sometimes fails to respond and surgery is usually offered as the next option. Again, surgery is successful in the majority of patients at improving symptoms and allowing access for nasal treatment that keep the sinus disease at bay. However, a very small minority of patients may have a relapse despite appropriate medical therapy and despite surgery. For CRSwNP, polyps may recur and up to 1 in 5 patients may need another operation within five years of their last. Until recently, this type of patient had few options other than to undergo repeated operations and / or courses of oral corticosteroids and they often suffered with a heavy burden of symptoms.

## **A new option for treatment**

Biologic agents are a new option that can be added into these patient’s treatment plans. They are usually considered for patients whose chronic rhinosinusitis with nasal polyps do not respond to surgery and appropriate medical therapies. Some patients with sinus disease may also be considered for biologic treatment because they have asthma which is difficult to control. Interestingly, even though this specific treatment was originally designed primarily to treat asthma there are many patients who will also notice a significant improvement in their nasal symptoms.

The availability of biological agents vary across different countries, as does the selection criteria used to determine if biologics can be used.

## **How biologic treatments work**

Biologic therapies are a new type of medical treatment. These drugs directly act on your immune system by preventing the

release of the chemical signals that trigger the body to respond by producing inflammation. In turn, there is a reduction in tissue swelling and it becomes less waterlogged. Polyps, if they are present, may stop growing or often significantly reduce in size. In turn, patients feel like they can breathe more easily through the nose, have less problematic nasal discharge, and may start being able to smell again.

Biologics are as effective as corticosteroids; both work to reduce inflammation but biologics do this in a more specific way so that there are fewer unwanted side effects. One of the most positive effects of biologic therapies is that they can reduce your reliance upon oral corticosteroids and can reduce the side effects associated with that medication.

## **Types of biologics**

There are several different subtypes of biologic agents that can be used for sinus disease, and it is likely that the list will increase rapidly over the next few years now that the technology has been established. Dupilumab is the first agent we have that is targeted directly at nasal polyps and scientific trials have shown that patients using this treatment were found to have a significant reduction in the size of their polyps, and reported an improvement in their nasal breathing, sense of smell, and quality of life.

Other biologics named mepolizumab, reslizumab, benralizumab and omalizumab are available and are more often used for patients whose asthma is their number one medical concern. It is likely in time that many more biologic agents will become available.

## **How, when and for how long you should use it**

Biologic treatment requires a series of injections. You will likely have some blood tests before receiving a biologic to help determine that they will be safe to use.

If you receive dupilumab, the first injection will be performed by your doctor, but you may be able to perform them at home by yourself later on. Injections must be performed every 2 weeks and are usually continued long-term, but your doctor will be very clear about your exact treatment schedule.

If you receive omalizumab, the dose will be calculated precisely according to your weight. Injections must be performed every 2-4 weeks and again are usually continued long term – but your

doctor will again be very clear on your exact treatment schedule also.

If at the end of your first trial period of the medication you have not found any benefit, you and your doctor may decide to discontinue it. If you do notice an improvement, you will have the option to continue this treatment. Symptoms will be controlled as long as the treatment is maintained. Unfortunately, if you stop the treatment, symptoms usually return.

The availability of biologics may vary across different countries and are likely to change over time.

### Side effects (and what to do if they occur)

Although side effects were reported in many of the trials for biologics, in most trials these were more common in patients who received a dummy or placebo injection, and biologics seem to be well tolerated in most patients. The most common side effects are injection site reactions (redness, swelling, itching), and a sore throat (nasopharyngitis). These side effects are usually short lived and settle without any medical treatment.

In a few patients, biologics can also cause serious side effects. Although these are very rare, you should be aware of their signs and if you notice them then you should immediately consult a doctor. First, these effects include allergic/hypersensitivity reaction such as uncontrollable itching, fever, skin rash, joint pain, swollen lymph nodes. The most serious form of these symptoms is called anaphylaxis which is recognised by very sudden onset of breathing problem, swelling of the face, mouth, tongue, and feeling very faint. If you have anaphylaxis symptoms: stop using your treatment and go to the emergency department of your nearest hospital right away.

Other reported side effects include eye problems such as a red, painful eye hair loss and joint pains, but these are also uncommon. As biologics are relatively new, there may be long-term side effects which have not yet been reported.

If you report other symptoms that are not listed in this leaflet and you think it may be related to your biologic treatment, you must also refer it to your physician.

### Potential interactions with other medications you take

Because biologics act on your immune system, you should be careful if you must be vaccinated. Notably, you should not receive a "live vaccine", which are vaccines that contain fragments of active infection. At the time of writing, commonly used live vaccines include measles, mumps, rubella, vaccinia, varicella, zoster (which contains the same virus as varicella vaccine but in much higher amount), yellow fever, rotavirus, and some types

of influenza. The first few coronavirus vaccines to have been discovered are not live – but you should always check the most up to date information.

### Patient's experience with biologics

#### Patient 1 reports:

"I was suffering from chronic rhinosinusitis with nasal polyps for more than 10 years. In addition to topical steroids, I was prescribed several courses of prednisolone and already had two surgeries. Despite these treatments, my polyps came back and I was still suffering from sinusitis. One year ago, my physician told me about a new treatment, named dupilumab. He made the first injections, and then I was instructed about how to do it. After a few weeks, I felt an improvement: my sense of smell came back and I could breathe through the nose. My sleep gets better and my life has changed. I have encountered no adverse effect"

#### Patient 2 reports:

"I developed nasal polyps 5 years ago and took oral steroids twice a year to shrink my polyps. But they came back after few weeks. So, I had a surgery to remove them. But again, they came back. In addition, I suffer from asthma and it was sometimes hard to control it. My ENT doctor and my lung specialist therefore prescribed me dupilumab. After the third injection, my polyps were gone. Now my asthma is controlled, my nasal breathing is normal and I enjoy smelling everyday odors! The only adverse effect I had was some itching on my calves"

### Frequently asked questions

#### Can I just take biologics for 6 months and then see what happens?

*Sinusitis with nasal polyps is a chronic disease. Therefore, it is recommended to take Dupixent as a long-term treatment. If you stop biologics after 6 months, your symptoms will probably recur; trials showed this happening within 8 weeks of the last injection*  
*If you are considering stopping biologics please meet with your physician first to discuss the reasons why, and any alternative treatments that may be considered. In some cases it might be possible to increase the interval between injections – in the trial of dupilumab, patients who were changed to 4 weekly injections after 6 months of treatment continued to achieve significant benefits.*

#### Is it better to start biologics before surgery or afterwards to stop the polyps coming back, like with aspirin desensitisation?

*Classically, biologics are indicated in patients with bilateral polyps who had had sinus surgery and who have uncontrolled disease despite surgery and systemic steroids treatment.*  
*If you never had surgery, surgery will most probably be proposed to you at first instance if your general health state allows, since it may*

adequately control your symptoms. If your symptoms are controlled after surgery, biologics are not indicated. If you relapse or feel no improvement at 3 months after surgery, biological treatment can be considered.

Studies investigating specifically the combination of surgery and biologicals are on their way, and recommendations may change with time.

#### **Will biologics stop me having reactions to alcohol?**

There might be different causes why you react to alcohol, ranging from allergies to hyperreactivity. In both cases, treatment with biologics may reduce this reaction, however this has not been formally investigated and is therefore hard to predict. Notwithstanding, we suggest to keep your alcohol consumption moderate.

#### **I have N-ERD – should I choose aspirin desensitisation, biologics or both?**

If you have N-ERD, you may be indeed a candidate for both treatments, however, in general they are not initiated simultaneously. The decision between one or the other is up to you and your doctor. It depends on your clinical characteristics, medical history, existence of co-existing disease or potential contra-indications to one of these treatments. No study has compared both of these treatments, so after comprehensive review of your medical history, your physi-

cian will propose you the treatment best suited to your situation.

#### **Which biologic should I choose?**

Although there are several biologics, Dupixent and Xolair are the only monoclonal antibodies that are currently approved (as of Jan 2021) for the treatment of chronic rhinosinusitis with nasal polyps. If you have asthma, you may be given other biologics. We do not have any trials that directly compare different biologics yet, and there is no simple test to determine which is likely to give the best result or the lowest side effects. It is usually up to your doctor to decide which treatment is best suited to your personal situation, although some healthcare systems will have restrictions on what choice is available. If you do not respond the biologic you have been given, you may be switched to a different type, and in very rare cases, biologics may be used in combination.

#### **What haven't I been offered a biologic?**

Biologics are usually considered in patients with severe CRSwNP. They are not yet available in all countries. In other countries, they may only be available for people meeting certain criteria, or may have co-payment requirements. Your ENT surgeon is the best person to explain if a biologic is available and a good choice for your disease.

## 12. Surgery for Chronic Rhinosinusitis

### The role of surgery in treating chronic sinus disease

The majority of people suffering with chronic sinus problems are successfully treated medically and do not require surgery. However, in some patients the underlying inflammation does not resolve with sprays, drops or tablets. In these cases, patients find that despite using these medicines their symptoms keep coming back or do not improve at all. In such cases, surgery can be considered.

### Different types of surgery

Endoscopic Sinus Surgery (ESS) is a term that surgeons use to describe the most common technique for operating on sinus disease. It was previously called “functional endoscopic sinus surgery” or FESS because it aimed to restore the normal physiology of the sinuses to produce mucus and drain into the main nasal cavity together with ventilation of the system to reduce inflammation. The word “endoscopic” means using a slim surgical telescope that enables all of the operation to be performed via the nostrils without any cuts or scars to the outside of your nose. On rare occasions, if your sinus disease is extensive or complex then an external cut may be considered - but your surgeon would discuss this with you before the operation. The term “sinus surgery” is used as an umbrella term to reflect that there is a variety of technical procedures that can be chosen to tailor the procedure to your sinus disease:

- Polypectomy: removal of nasal polyps
- ‘Mini ESS’: approach involving simple ventilation of the maxillary and anterior ethmoid sinuses (usually in mild disease)
- ‘Full House ESS’: opening of all sinuses including maxillary sinus, ethmoidal sinuses, sphenoid sinus and frontal sinus
- Extended endoscopic surgery: usually performed as a revision surgery in cases of severe resistant chronic rhinosinusitis
- Balloon sinuplasty: gentle stretching of a sinus opening using a small balloon to enhance the natural drainage path of the large nasal sinuses suitable in only selected cases
- ESS is usually performed when you are asleep (general anaesthesia). In some cases, it can be done under local anaesthetic which allows surgery to be performed while you are awake.

### How does surgery work?

The goal of surgery is to open any sinuses which are inflamed and to create an environment which reduces the risk of that inflammation returning after surgery. The goals of surgery,

therefore include:

- Allowing washes and medicated sprays to get where they need to go
- Achieve adequate ventilation
- Improvement of sinus drainage
- Restoration of normal nasal functioning

This is done by removal of polyps (if present), small amounts of bone and inflamed tissue that are blocking the sinuses.

### Key steps in endoscopic sinus surgery

The ostiomeatal complex, or the common sinus drainage unit, shown in the image below, is the focus of almost all endoscopic surgical technique, which largely aims to enlarge the sinus ostia to improve drainage of secretions and access to topical therapy.

Partitions that divide the sinuses into a series of smaller cells are carefully removed creating larger open cavities and widened ‘ostia’ or sinus openings.

### Risks of surgery

In an ideal world, we would be able to offer a treatment for sinus disease that was both remarkably effective and also completely safe. Unfortunately, virtually all medical treatments whether tablets, sprays, or operations will be associated with some risks. Each time a new treatment is started, your doctor will discuss with you the benefits, risks, and alternatives (including what would happen if you had no treatment at all).

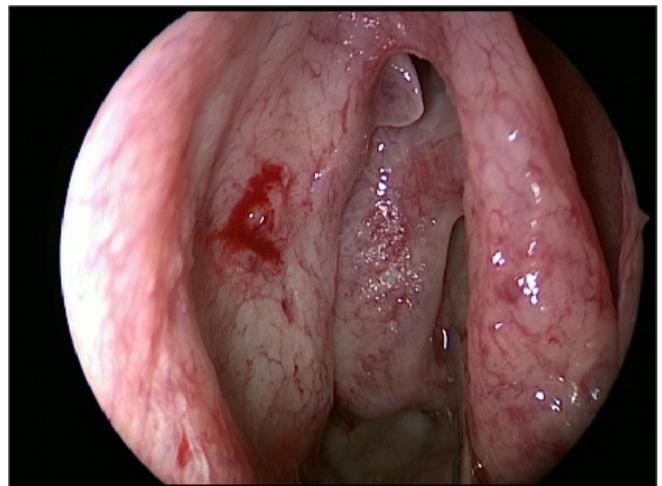


Figure 12.1. Endoscopic view of the RIGHT ostiomeatal complex. The uncinate bone and ethmoid sinuses are intact, the natural opening of the maxillary and frontal sinuses are not visible.

All surgical procedures have consequences like a small amount of post-operative bleeding, and it is quite common to suffer regular but short-lasting nosebleeds after ESS. However, if the bleeding is severe or prolonged, help should be urgently sought. Infection is reasonably common after ESS and if you suffer an infection then you should discuss with a doctor whether antibiotics are required.

Minor complications are self-limiting and include damage to the eye socket that presents as a 'black eye' or swelling of the skin around the eye caused by infection, or a watery eye. The contents of the eye socket may be damaged resulting in impaired eye movements or loss of vision, but these are exceedingly rare.

There is also a very small number of patients who may have an injury to the portion of the skull that shares a party wall with the sinus cavity. This can cause a leak of the fluid that normally surrounds the brain (cerebrospinal fluid or "CSF"). If this would arise during surgery, the surgeon can repair it with no additional related complications postoperatively.

Surgeons are very mindful of the impact that these complications have on their patients and do everything within their power to minimise the potential risks. There are many scientific papers that examine the rate of complications during sinus surgery and report these estimates:

- Minor bleeding or infection: common
- Black eye: 1 in 500 patients
- Severe bleeding, CSF leak: 1-2 in 1000 patients
- Visual disturbance: less than 1 in 10 000 patients

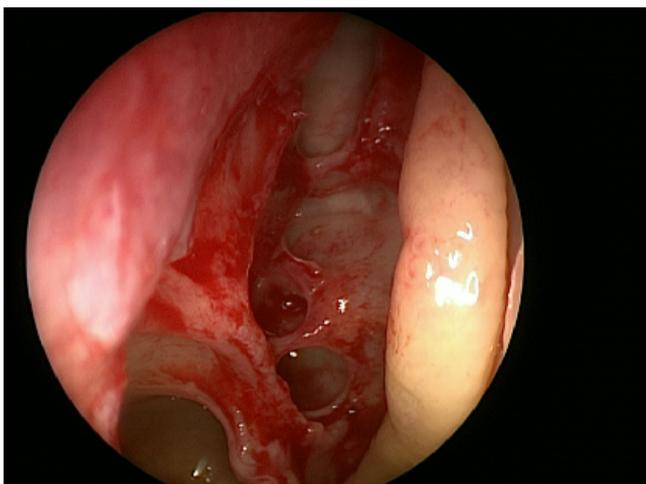


Figure 12.2. Completed RIGHT basic endoscopic sinus surgery; the uncinata bone has been removed exposing the natural ostium of the maxillary sinus, which has been enlarged. The anterior ethmoid cells have been opened creating a common cavity and allowing unobstructed access to the frontal sinus.

However, it is important to note that these figures come from large databases and may not be relevant to your surgeon or your sinus disease. Your surgeon will be happy to discuss these risks with you before planning an operation.

#### Outcomes of surgery and risk of recurrence

Overall, you should expect a significant improvement of symptoms that are related to chronic rhinosinusitis such as blocked nose, smell, nasal discharge, and mucus running into the back of your throat (although change in post-nasal drip is more unpredictable). Successful outcome of the surgery is reported by more than 8 out of 10 patients. In most cases, as CRS is an inflammatory disease and is not cured by surgery, the aim is creating an environment that allows for nasal medications to get access to the sinuses in order to be effective. Therefore, having surgery does not remove the need for nasal treatments and they are likely to be used for the rest of your life. Giving the chronic nature of sinus inflammation, approximately 1 in 10 patients will require revision surgery within 3 years. Patients with severe asthma or aspirin intolerance are more likely to require revision surgery than other patients.

#### What are packs and how are they used

Depending on the extent of the procedure and surgeon's preference, you might need what is called nasal packing. This is when your doctor places sponge-like material in the nasal cavity to absorb blood or other fluids right after surgery. It also may be soaked with anti-inflammatory medication that may improve healing after the surgery. Your doctor will inform you if packing dissolve by itself, or if it must be removed.

#### What to expect during recovery

The healing process of the nasal cavities varies from patient to patient, and may take just a few days after polypectomy, 'mini' ESS and balloon sinuplasty while it usually takes 2 weeks for 'full house' ESS. Some patients may have mild nasal pain and headache, especially during the first week after surgery, which can be well controlled using paracetamol/acetaminophen tablets as needed.

Many patients are able to return to normal daily activities after 8-10 days but it may take longer before you feel fully recovered. You should usually plan to take two weeks off from work, sport, and exercise although everyone recovers at different rates.

Some things you will need to remember during the recovery period:

- Sleep with your head raised, perhaps using an extra pillow, for a while.
- Avoid blowing your nose for a week or so, except after nasal rinsing.
- Try to keep your mouth open when you sneeze. This will take some of the pressure off your nasal cavities.

### Post-operative medications and how to use them

In the postoperative period, nasal saline irrigations are strongly recommended to clean the nose from secretions, blood clots and nasal crusting; they should be repeated at least twice per day. Nasal rinses can be done using a squeeze bottle, neti pot, or syringe, lean forward over the sink, at about a 45-degree angle. The tip of the device should go inside your nose, no further than a finger's width. Keeping your mouth open, squeeze the bulb syringe or bottle, or tilt the pot to pour the water into your nostril. Remember to breathe through your mouth, not your nose. The saltwater will run through your nasal passages and drain out of your other nostril and maybe your mouth. The procedure should be repeated with your other nostril, and, finally, you can blow your nose gently to clear out the remaining solution. They are usually started soon after surgery but your doctor will advise on this.

Nasal corticosteroids, administered in addition to nasal irrigations or as nasal spray, are effective in preventing polyp recurrence for patients affected by chronic rhinosinusitis and should be continued for long term, based on ENT doctor advice.

In very selected cases, your doctor might also prescribe you also an antibiotic treatment to be taken after surgery, however this is unnecessary in most cases.

At the time of your hospital discharge, your next follow-up appointments will be scheduled. During the outpatient visits, the sinus openings are checked using and in your nostrils. In some cases, debridement (active cleaning) might be necessary to promote the healing process of the nasal cavities by suctioning secretions or blood clots and removing nasal crusting.

Role of septoplasty and turbinate surgery at the same time

Some patients may have sinus surgery combined with other nasal procedures such as:

- Septoplasty: straightening of the cartilage in the middle of your nose
- Turbinoplasty: improving the airflow by remodelling some of the bone in the nasal passage called the inferior turbinate

These procedures are useful especially for those patients complaining of severe nasal blockage non-responsive to medical treatments. If appropriate for your case, the ENT doctor will extensively discuss with you the need for such procedures before surgery.

### Patient's experience with endoscopic sinus surgery

#### Patient 1 reports:

I have experienced multiple episodes of rhinosinusitis with nasal obstruction, facial pain, nasal discharge, and secretions running into the back of my throat. I don't get no relief with any nasal spray, even after long courses. I decided to trust my ENT doctor who proposed to me a surgical procedure called ESS to solve

my problem. The same evening after surgery I was sleeping at home in my bed. I followed the postoperative medical prescriptions meticulously, including many nasal irrigations every day. My surgeon checked my nose with the telescope two times after surgery in the first postoperative month. Now, three months after surgery have passed, and I could not have asked for a better outcome.

*Video 1 shows the final result obtained three months after ESS, with patency of sinuses openings.*

*Link: <https://1drv.ms/v/s!AoGcQbw7FUgNiNdPPzhuqbyvT6J0CA?e=FVBXeo>*

#### Patient 2 reports:

I was submitted to surgery for nasal polyps. Few days after hospital discharge, I had to go back to the steel mill where I work and I didn't have much time for medications. One week after surgery, I began to have purulent nasal discharge and bad smell from my nose. So, I pushed my appointment up to get a medical consultation immediately. The endoscopic evaluation of my nose revealed an infection and the medical doctor performed a medication to remove crusting and to suction secretions. The doctor did not seem concerned by it but advised me to start an antibiotic treatment, so I focused on getting better. Now the problem is solved and I have learned that it is important to always perform prescribed care, especially after surgery.

*Video 2 shows the nasal infection developed after surgery.*

*Link: <https://1drv.ms/v/s!AoGcQbw7FUgNiNdO30Fz7svLOWW-bg?e=pDNXeJ>*

#### Patient 3 reports:

At the time of referral to tertiary centre, I have had already three surgeries for nasal polyps. Doctor explained that in my case, the chronic rhinosinusitis was complicated by asthma and aspirin intolerance where both appropriate medical therapy and surgery are essential. I was really scared to go 'under the knife' once again, especially because my last surgery was just a couple of years ago. At last, I made up my mind. The surgery went well and lasted less than two hours. My nose was packed for 24 hours and the day after surgery I began to breathe again. I've then started nasal treatments and I've learned that they should be used for the rest of my life: it's not a problem, as long as I can continue to breathe through my nose like now.

*Video 3 shows the final result obtained six months after extended endoscopic endonasal surgery, with patency of sinuses openings.*

*Link: <https://1drv.ms/v/s!AoGcQbw7FUgNiNdLoTWpXSsaLMIRHw?e=AKg33x>*

## Frequently asked questions

### When should surgery be considered?

Nasal surgery should be considered when the medical treatment recommended by your ENT specialist has failed to improve your symptoms or to achieve long term control despite ongoing use. It might also be considered if there is evidence of complications, or if you are unable to use medical treatments due to side effects or other conditions.

### I really do not want to have surgery, are there any risks if I refuse?

If your doctor feels that surgery is the best choice for you, it usually means that you did not respond well to medicines. In vast majority of cases, postponing or not having a surgery would result in ongoing uncontrolled symptoms such as nasal blockage or loss of smell which might get worse over the time. Although it is very unlikely to be a risk to your general health, rarely, inflammation may spread from the nose to the brain or your polyps might expand and cause pressure on your eye socket or nasal bones.

### Do polyps always grow back after surgery?

Giving the chronic nature of sinus inflammation, approximately 1 in 10 patients with nasal polyps will require revision surgery within 3 years, and 1 in 5 within 5 years. Patients with severe asthma or aspirin intolerance tend to require more operations than other patients, and often do not get as much improvement in their symptoms despite using the same (or even more) medications. It's paramount to use nasal treatments regularly as prescribed in order to prevent, or at least slow down, the polyps' regrowth.

### Is sinus surgery painful?

No, not really. Some patients may have mild nasal pain and headache, especially during the first week after surgery, which usually is well controlled using paracetamol/acetaminophen tablets as needed. Your doctor may prescribe stronger painkillers but these are often not needed. You will feel quite congested, and this might be helped by using salt water rinses after surgery.

### Will I have black eyes after surgery?

Very unlikely, but it may happen. If that occurs, bruising will resolve within 10 days and you should not blow the nose during this time.

### How long do I have to stay in hospital after my operation?

This depends on the extent of surgery but in most cases, ESS is performed as a day-case procedure meaning that you are discharged on the same day.

### How long is the recovery?

The healing process takes just a few days for polypectomy, 'mini' ESS and balloon sinuplasty while it usually takes up to 2 weeks for 'full house' ESS. Many patients are able to return to normal daily activities after 8-10 days but it may take longer before you feel fully recovered. You should usually plan to take two weeks off from work, sport, and exercise although everyone recovers at different rates.

### I am having revision surgery – is it riskier?

Revision surgery is performed in patients who have been already operated, therefore distorted anatomy and scarring may make it more difficult for your surgeon. They will be happy to discuss these risks with you before planning an operation.

### I'm on aspirin after desensitisation – do I have to stop it for surgery?

Endoscopic sinus surgery is usually performed before starting aspirin desensitization treatment. However, if you are currently on aspirin after desensitization and surgery has been scheduled for you, the aspirin treatment can usually be continued. Your doctor will advise if you need to reduce the dosage and how to do it. There are also some useful guides for aspirin management on the Samter's Society website (see section on patient resources).

### Will surgery solve my problems forever?

Many people can achieve long-term control of their symptoms but will usually require ongoing medical management. However, there is a chance that further surgery may be required in the future. Your surgeon will discuss different ways to reduce the risk of needing further surgery with you.

## 13. Taking part in clinical research

### Clinical trials

Patients are an essential part in clinical research, and not just as trial participants but increasingly are involved with designing clinical studies, and helping to implement their findings.

### Helping with the design of clinical research studies

In the same way that we are trying to involve patients in all choices regarding their care, by providing all information regarding risks and benefits and reaching shared decisions, researchers are increasingly involving patients in the design of research projects and trials. This helps to ensure that the treatment or test being investigated is something that patients want, need and would accept as a treatment, that the study is performed on a way that patients would feel comfortable taking part in, and that the answers provided by the research project address issues most important for patients. Put simply, it helps ensure that research is worthwhile from a patient point of view.

### How can patients get involved in research?

Patient involvement in research design can involve lots of different methods, for example;

- Being interviewed about how your illness affects your quality of life in in what ways current treatment to identify topics for future research
- Looking at a list of research ideas and saying which ones are the most important
- Being shown examples of different trials and telling an interviewer your thoughts – whether you would be willing to participate, any concerns or questions you have about the study design
- Filling out questionnaires to help decide what outcomes (questions) should be measured in a study
- Reading patient information sheets to make sure that they are easy to understand

Taking part in helping to design research studies usually involves giving up some of your time, and sometimes travel but do not involve undergoing treatment. They are usually voluntary, although costs of travel are often refunded, and you will often be given refreshments if you are spending a long time at a meeting. In some cases, you might also be paid for your time.

You might be asked to take part in small group workshops, to take part in telephone interviews or fill in written or email surveys – the team will explain how they will do this so you can

decide if you are comfortable in that setting. The team will likely be able to make adjustments for any special needs and will also understand that for many patients it can perhaps be a little intimidating sharing your views in a group, and will be there to make everyone feel comfortable and to give everyone time to have their say if they want.

You are of course able to say no if you are asked to take part – there is usually no direct benefit to yourself, but many patients enjoy the chance to help change future research, and some go on to play a large role in research projects – most big trials now have a patient representative on the trial team, and a patient panel that feed into the trail on a regular basis.

It is important to remember that when you are giving your opinions on study design, there are no wrong answers. Your experience as a patient is actually often far more useful than 20 or 30 years' experience of a researcher – and it's important that you feel able to be honest. Patient input can really help save researchers from making mistakes that would make their study worthless, as patients often quickly spot problems that researchers have overlooked, so they will really want to hear what you think, good or bad - not what you think they want you to tell them!

### Taking part in a clinical trial

There are many ongoing research projects that aim to develop new treatments for CRS or to work out how to improve the effectiveness of current treatments and your doctor may ask if you wish to join a study.

There are different types of trials and your team will carefully explain what is involved, provide you with written information to take away to read through with friends and family, and will give you time to consider carefully if you want to participate before making a decision. Many patients are keen to take part in trials but not everyone will want to do so. There is no obligation to take part and your medical care would not be affected if you say no.

Observational studies follow patients over time, often to study how a disease changes over time. Patients will often be asked to complete questionnaires or investigations on a regular basis. There is usually very little risk in taking part in observational studies, other than giving up your time, and often patients benefit from being monitored more closely than normal.

Clinical trials are usually run to test new treatments, or to find out which or two or more treatments are more effective. Trials are performed when there is no pre-existing evidence that one treatment option is better or worse than another, or in the setting of new treatments, no evidence that it is better or worse than doing nothing or continuing with standard care.

Patients are often divided into 2 different groups who receive different treatments, and the allocation to a treatment group is usually randomised (often by a computer which 'tosses a coin' to decide). Studies may be placebo controlled, where one group gets a new treatment, but the other group gets an inactive version, and in these trials both the doctors and patients may not know which treatment they are getting (this is called blinded study). In most trials the numbers in each treatment group are the same – that is the chance of getting one group or the other would be 50:50 but sometimes there is a higher chance of getting one treatment than another, or there may be more than 2 different groups.

#### **Keeping patients safe during research**

Clinical trials must comply with very high standards of care to maintain the safety of patients taking part. Trials are very carefully assessed before they can start to recruit patients and steps are put in place to minimise any risks. They are closely and regularly monitored. There will always be a contact person who can be reached in case of any problems, and in blinded studies, it is possible to find out what treatment has been given in case of emergencies.

Patients may withdraw from a study at any time, if they suffer any side effects, if they feel that their condition is not improving, or simply if they feel they no longer want to take part. Some trials will allow patients to move between treatment groups, while others will allow patients to receive active treatment after the trial is completed if they have received a placebo drug. Your doctor will be able to tell you all about this in advance. Your doctors first priority is always your well-being and safety, and your care will not be affected if you withdraw from a trial.

#### **What are the benefits of taking part in a clinical trial?**

You might be given access to new treatments that are not otherwise available

You will often receive more frequent check-ups, either by phone or in person – and this means that patients taking part in trials often get better improvements in their health even if they don't receive the investigational treatment

The trial may lead to the development of new treatments that you and other patients may benefit from in the future

You may sometimes be rewarded for taking part – although most trials are voluntary.

#### **What are the risks?**

The new treatment may not be effective and in some cases may cause side effects. Known side effects will be discussed during the process of informed consent, but with new drugs there may be some unknown risks

You may not receive any treatment (watchful waiting) or in other cases receive a placebo drug – an inactive drug designed to look the same as the investigation treatment.

You may have more visits to the hospital than would be required if having the standard care.

#### **What happens next?**

You will usually be given a detailed explanation and written information sheet, and then some time to carefully consider whether you wish to join the study. The research team will need to check that you meet the inclusion criteria for a study, and that you don't meet any of the exclusion criteria – for example, studies may be looking at only certain types of CRS, and may exclude patients who are already taking certain medications or have other associated conditions.

If you meet the criteria and wish to take part you will be asked to sign a consent form, and will then be allocated to a treatment. Your team will let you know what this involves, how often treatments and study visits are required, and how long the study continues for. They will also let you know what happens at the end of the study and will usually keep you up to date with the results of the study

#### **What do you need to know before you make your decision?**

The Patient Information Sheet should include all the information you need in order to decide whether to participate. It should cover all of the following questions, but you may want to ask your doctor / research nurse if you still have any questions

- What is this study trying to find out?
- What treatment or tests will I have as part of the study and will they hurt? Will you give me the test or lab results?
- What are the chances I will get the experimental treatment or the placebo, and will I know what treatment I am having?
- How will this be decided?
- What are the possible risks and benefits of the study treatment compared with my current treatment?
- How will I know if the treatment is working, and what happens if it does not work?

- How long will the clinical trial last?
- Where will the study take place?
- Will you provide a way for me to get to the study site if I need it?
- Will being in the study cost me anything? If so, will I be paid back for expenses such as travel or parking?
- Will I receive any other payments for taking part in the study?
- How will the study affect my everyday life?
- What steps are taken ensure my privacy?
- How will you protect my health while I am in the study?
- What happens if my CRS gets worse during the study?
- Does the study allow me to change treatment group?
- Can I take my regular medicines while in the trial?
- Can I take emergency medicines while in the trial such as antibiotics?
- Who will be in charge of my care while I am in the study?
- How will you keep my doctor informed about my participation in the trial?
- If I have to withdraw, will this affect my normal care?
- Will you follow up on my health after the end of the study?
- Will you tell me the results of the study?
- Who do I contact if I have more questions?

### Patients' experience of both taking part in a clinical trial and involvement in trial design

#### *Patient 1 reports:*

"My first personal experience of clinical research was when I was diagnosed with bladder cancer more than ten years ago. I underwent surgery and it was then explained by my specialist nurse that a course of treatment stretching over the following three years would be needed, involving some 24 visits to the clinic. Added to this was a mention of a research project which was looking at the effectiveness of additional medication in the form of specific vitamin and mineral supplements, and would I like to take part. Being recently retired and no longer under time pressures, I agreed and was given an information sheet about the work.

A meeting was arranged with the research nurse who took me through the background to the study and that the trial involved taking either the medication or a visually placebo which neither I nor she would know which I received. I signed the consent form and was given a diary in which to record the taking of the medication and a prescription for the first set of medication and sent me off to the hospital pharmacy. This was not a good start since it involved more than an hour wait to receive it! I also quickly found that the daily diary rapidly became a chore, since it consisted of box ticking for taking the medication and experience or absence of a range of symptoms, which were almost invariably absent. However, at the next hospital visit I was told that the diary couldn't be changed, but on the positive side I

would receive further medication directly from the research nurse. Some further discussion enabled aligning future appointments with those for my mainstream treatment, hence saving extra journeys into the hospital. My participation continued for over twelve months, but then I received a phone call from the nurse to tell me that the trial was being halted early and I should stop taking the medication. Rather to my surprise I heard nothing more.

This may sound a somewhat negative experience, but it provided some fruitful learning for when I became a patient representative on a team designing a CRS treatment research project. I was fully involved in designing the trial to give the best patient experience, including its organisation, information leaflets, diaries and communication plan, and that too provided some further learning. For instance, by chance I underwent one of the procedures involved in the trial at the time the patient diary for it was being finalised, so was able to test it first hand and provide user feedback. Clearly, any opportunity to "road test" documentation and diaries on actual patients during planning for a trial should be explored and implemented. Another learning experience was in the compilation of the patient information leaflets. These followed standard templates required by the sponsoring research centre, which, from my experience of standardisation in industry I fully supported. However, the need for some degree of flexibility to accommodate different types of trial and minimise repetition and irrelevant information was clearly needed in order to produce the most concise and digestible document. All learning which can feed into and improve the next trial."

It's clear that this patient's first experience of taking part in a trial, over 10 years ago was not a very positive experience. The involvement of patients in trial design now helps to ensure that trial visits are kept to a minimum, and that completing diaries and other questionnaires is made as simple as possible – usually with options to reply by text, by email or using paper diaries, as everyone is different. Sometimes trials allow access to new treatments, but rarely, as in this case, trials are stopped ahead of schedule if it becomes clear that the treatment either works very well, or doesn't work at all. Nowadays, patients will be kept informed at all stages of the trial if there are any changes and will be sent a report after the study has finished if they would like to know the findings. The participant below has had a much more positive experience and we certainly hope that this is now what can be expected by anyone taking part in research. Please remember that the decision as to whether you wish to take part is yours and it will not affect your care if you choose not to or change your mind at any point. However, it can be rewarding and is an essential step to developing better treatments that you might benefit from in the future.

**Patient 2 reports:**

I was asked to take part in a clinical trial in 2017. I was very apprehensive at first as I had very little knowledge of clinical trials.

From start to finish I felt very supported by my consultant and the research nurse, who was at the end of the phone whenever I had any queries and was very attentive throughout the whole clinical trial.

I was given an information pack that clearly outlined when I would be required to take the injection, what dates I'd be seen in clinic for tests etc and what the plan was for the whole duration of the clinical trial.

A slight disadvantage is not knowing whether you are receiving the drug or the placebo. However, through undertaking clinical trials you do your bit for science and improve the chances of having access to a drug that will help you and others in the future.

I had an excellent experience overall and would highly support and encourage others to take part in clinical trials.

**Useful links**

<https://www.clinicaltrialsandme.co.uk>

## 14. Loss of smell

### Living with loss of smell

It is an uncomfortable fact that many people will not experience relief from the sometimes unspeakable pain that smell loss causes. With the relationship between smell problems and quality of life now well-established, long-term support needs to address food issues, depression and the isolation experienced through smell disorders, which can involve both reduced ability to smell (known as hyposmia, or anosmia if there is complete loss), but also distortion of smell (known as parosmia or phantosmia).

### The personal consequences of smell loss

Smell loss is indescribable to anyone who has not experienced it and this fact alone can create a barrier between the patient and their doctor. It is not just the loss of the food/eating experience, but loss of the global experience of pleasure. The natural world, the time of day and year, and links that transport us to happy memories of the past – all these fall victim to smell loss, and all of them are tied up with strong and positive emotions. Our relationships with family and friends can falter when the reassuring feedback of our loved ones' smell is not there. Without these things, and the poignancy that accompany them, we are less ourselves, untethered from the normal human experience and feelings of joy. Many self-soothing mechanisms are also tied to smell – even a reassuring hug – and during the kind of long-running bereavement that accompanies loss of smell, this simple self-help method is elusive.

Living with smell loss has external consequences too. Because of the recurring feeling that “no one understands”, “people forget”, “they tell me I should be grateful it isn't worse”, frustration mounts and alienation persists. People adopt coping strategies for this when dealing with others which can include pretending that they do smell, or resisting the need to bring it up in conversation. With these things come resentment.

Helping someone accept and adapt is difficult, and much depends on the outlook of the individual. For a successful way forward, there needs to be empathetic support from the doctor, and where possible, a peer group. The following may be helpful in this process:

### Food strategies

Assistance will be needed in adapting to a new way of seeing food. For this to be successful, the individual needs to be willing to be curious and a “sensory detective” in exploring nuance in texture, true taste, temperature contrasts, and colour combi-

nation on the plate. For those with parosmia, a willingness to determine trigger foods through experimentation, and discover also “safe” foods to establish a workable diet that is nutritionally balanced is vital. As parosmia can shift over time, the explorations need to be ongoing. In an overall sense, this tunes the person to be more observant of their experience of eating but also be more open to engaging with food.

It is important to avoid excessive use of salt or sugar, but to experiment with spicy, bitter or umami (a ‘meaty’ taste found in meat, mushrooms or broth) tastes. Combining tastes (for example, using ‘sweet and sour’ sauces) may also make food taste more interesting.

Further advice is available from the patient support groups listed below.

### Personal safety

Our sense of smell plays an important safety role. Patients with a poor sense of smell are at higher risk of food-poisoning and exposure to fires. It is essential to have a smoke detector, which is checked regularly, and to follow expiry dates on foods.

### Positive ways of seeing the world

An open mind that seeks to focus away from the condition is central for adapting to life-long smell loss and is easier said than done. Getting out of doors and appreciating the sensory experiences of nature, even without smell, has great benefits. Absorbing hobbies that focus the mind elsewhere and require use of motor skills also seem to be very helpful. It is perhaps the sensory input of touching jigsaw pieces, knitting needles, woodwork, etc, which assists in this. Meditation, mindfulness and yoga are all practices that have been reported by patients as being a solace in a world without smell.

### Peer support

Once clinical interventions have been exhausted, patients need the support of their peers. Advice about positive ways of seeing the world, for instance, might be better delivered from those who have already adopted these techniques, have experienced the bereavement, and have a ready supply of genuine empathy, and time, for the situation. The patient's need is not “just” to be heard. It is to be heard and understood.

Peer support can provide many different things: safe spaces to unload, a chance to be heard by people who understand, opportunities to form bonds with people who are in different places along their journey of adaptation. This can go a long way to

helping the many who experience the anxiety of the unknown as they begin to accept their diagnosis. It is this anxiety which causes problems that are separate from the smell dysfunction itself. A peer group is a friendly and supportive environment to sit and decompress.

### **Patients' reports of loss of smell and its impact on their life**

#### **Patient 1:**

"There were no nasal problems until I turned 30 and began to suffer from what I thought were recurrent colds and bouts of bronchitis, with breathing difficulties. It wasn't until my late husband and I went to live and work in Hong Kong, that I was diagnosed as having asthma and allergic rhinitis. I was given scratch tests which showed up mild allergies to a dozen or so things (no foods) all environmental. The scratch which showed up the worst reaction was to house dust.

I am also allergic to aspirin and ibuprofen. This I was eventually told, is Samter's syndrome or triad. (Asthma, nasal polyps, aspirin).

My sense of smell was coming and going at this stage. The rhinitis tended to be worse in the morning and my sense of smell vanished. By lunchtime it had calmed down and smell returned.

The rhinitis was treated with nasal sprays and anti-histamines and at one point I was receiving an annual steroid injection which worked wonders but this was withdrawn because of side effects such as osteoporosis.

In the late 1990s I was referred to an ENT consultant and a scan showed that I had significant polyps in my nose and sinuses and an operation was recommended. By this time my sense of smell had all but disappeared apart from the rare occasion when I was prescribed Prednisolone to treat asthma, when it returned briefly each time.

A friend had recently had the same operation and reported that on his exit from the hospital, the first thing he noticed was the smell of newly mown grass. I was very positive and looked forward to having a similar, happy outcome. However, it was not to be. The consultant reported that there was a large polyp covering the olfactory receptors and he didn't remove it in case they were destroyed completely. He felt that one day (and has this day come?) there might be some serious research into loss of the sense of smell and possible treatment. He said that at that time there was no real appetite for serious research. I think he said something to the effect it wasn't very "glamorous".

Since then, I have had 2 further polypectomies. On a follow up appointment to the 2nd I asked the registrar whether I might regain my sense of smell one day. Without lifting his head from writing, or even glancing at me, brusquely said "no, you may

never get it back". I left the office feeling quite hopeless. That was one of my worst moments. The attending nurse ran after me and said I shouldn't take any notice and to get a second opinion.

Roll on to the 3rd polypectomy June 2019. Basically, no help or hope regarding the return of my sense of smell."

#### **Patient 2:**

" After just four days of taking oral steroids, my sense of smell and taste returned as if by magic. The improvement to my life and well-being was nothing short of sensational, although it didn't last. The wonderful intensity of returned smells and flavours showed what my senses were capable of. It seems to me that something is masking the olfactory process. Perhaps one day research will reveal what is happening in cases like mine, and indeed, will indicate how the condition may be treated. In future, if I find myself struggling, I will now be able to ask for a repeat prescription.

My experience is that doctors have so much on their plates, anosmia is not given the attention it deserves. It is not life threatening, but does diminish one's quality of life, in some cases to a degree unimaginable to a non-sufferer."

### **Treatment options for loss of smell**

Different treatment options are covered in more detail in separate sections of this guide, but we have summarised options which are particularly relevant with regards to loss of smell from chronic rhinosinusitis.

Smell loss is more common in CRS with nasal polyps, but may occur in CRS without nasal polyps, particularly in the setting of type 2 inflammation. The following options are usually considered;

Topical nasal steroids; these may be given as a spray, or may be more effective in the form of drops or added to saline and used as a rinse or soak, especially after sinus surgery

Oral steroids; these often achieve dramatic improvements in sense of smell but unfortunately benefits are often short-lived and should be followed with nasal steroids to maintain benefit for as long as possible.

Sinus surgery; this may achieve improvements in sense of smell but unfortunately benefits may not be long-lasting and surgery should be followed with nasal steroids to maintain benefit for as long as possible.

For patients with type 2 inflammation, which includes the majority of patients with nasal polyps, biologics (in particular dupilumab) likely offer the most effective treatment in terms of



restoring sense of smell and can be used to achieve long-term improvement. They are currently licenced for use in the US and Europe although access to these medications will vary in different healthcare settings, and the cost of treatment may not be reimbursed.

Losing your sense of smell and taste can have a huge impact on your quality of life. It can be difficult to access support and it can be hard for friends and family to understand how it affects you if they have not experienced it themselves. There are two patient groups who provide resources to help and allow you to share experiences with others who have been affected – AbScent ([www.AbScent.org](http://www.AbScent.org)) and Fifth Sense ([www.FifthSense.org.uk](http://www.FifthSense.org.uk)).

## 15. N-ERD

# A guide developed by patients of the Samter's Society

<http://www.samterssociety.org>

### What is N-ERD?

Non-steroidal Exacerbated Respiratory Disease (also called N-ERD, Aspirin exacerbated respiratory disease, AERD or Samter's Triad) is a chronic disorder of the immune system. The main symptoms of the disease are asthma, nasal polyps, and respiratory reactions to aspirin and NSAID medications such as ibuprofen. The disease usually develops in adulthood, although cases have also been reported in children and adolescents. N-ERD is most commonly diagnosed between ages 30 and 40. Avoiding aspirin and NSAID medications is not enough to control the symptoms of the disease.

### Do I have N-ERD?

Because of the above situation, it is common for patients to suspect that they have the disease before a doctor diagnoses them. Signs that you might have N-ERD:

- Asthma or nasal polyps that began in adulthood
- Asthma or nose and sinus symptoms after taking aspirin or NSAIDs
- Asthma or nose and sinus symptoms after drinking alcohol
- Nasal polyps that return quickly after surgery
- A complete loss of sense of smell

Not all N-ERD patients have asthma. Asthma in N-ERD can range from non-existent to very severe and difficult to treat. About 5% of N-ERD patients never develop asthma or have asthma symptoms only after ingesting an aspirin or NSAID medication.

If you think that you might have N-ERD but haven't been diagnosed yet, you may wish to avoid aspirin and NSAID medications until you are able to be seen by an expert on the disease. If you have some of the symptoms of N-ERD but aren't sure if you have reactions to aspirin or NSAID medications, you may need to undergo an aspirin challenge with an allergist to receive a diagnosis. Don't attempt to take aspirin or NSAIDs on your own to see if you would have a reaction. N-ERD can cause life threatening reactions and a challenge needs to be done under medical supervision.

### Finding a doctor who understands N-ERD

Research has found that around 7% of adults with asthma have N-ERD. In patients with both nasal polyps and asthma the percentage is much higher – around 40%. The disease is not uncommon, but many patients go undiagnosed due to lack of awareness of the disease in the medical community. Doctors

who don't specialize in the disease such as primary care physicians and emergency personnel are often unfamiliar with it. Specialists such as ENTs and allergists are more likely to have heard of the disease, but not all of them are familiar with current knowledge on how to treat it.

Unfortunately, it is common for patients to have difficulty finding a doctor knowledgeable about N-ERD and the recommended treatments. It can make a big difference in your quality of life if you are able to be seen by a doctor who specializes in N-ERD. There is a map of physicians who specialize in N-ERD and other patient-recommended doctors available on the website [www.samterssociety.org](http://www.samterssociety.org). It can also help to educate yourself on the disease so that you can better advocate for yourself. Many doctors will be willing to learn about the disease in order to help you feel better. If your doctor is not familiar with N-ERD, one step you can take is to print some medical literature for them to review. There are also a variety of printable handouts available on The Samter's Society website. When talking to your doctor, don't be afraid to be assertive. Many physicians don't understand the impact that smell loss has on quality of life, but smell loss is the symptom that N-ERD patients report impacts their quality of life the most. Sense of smell is important for enjoyment of food, detecting danger, and even plays an important role in memory and social bonding.

### Finding effective treatments

There are treatments that can help, but they aren't always easy for patients to access. The most important thing you can do to improve your quality of life is to be seen by a doctor who specializes in N-ERD. Most patients will need to be on an asthma controller medication such as an inhaled steroid or an inhaler that combines a steroid with a bronchodilator. Generally, N-ERD patients have a more difficult time accessing effective treatments for sinus disease than asthma. Asthma can be life threatening and most doctors take uncontrolled asthma seriously. Sinus symptoms like smell loss and nasal congestion are often seen as less important, even though they can make life miserable for patients. Allergy treatments like antihistamines and allergy shots are not usually very effective. Only about half of N-ERD patients also have environmental allergies and allergies aren't the cause of N-ERD symptoms. Even when environmental allergies are controlled, patients will continue with asthma, nasal polyps, and chronic sinus inflammation without additional treat-

ments. Fortunately, there are a variety of treatments that can be beneficial for N-ERD including anti-leukotriene medications, aspirin desensitization, effective nasal steroids, and biologic medications. We will address a few of the most important N-ERD treatments below.

### Effective nasal steroids

Regular nasal sprays aren't very effective for nasal polyps since they aren't able to penetrate the sinuses deeply. There are more effective nasal steroids available that can be added to a sinus rinse or used to soak nasal polyps. One such medication is budesonide (Pulmicort) which is a steroid liquid that is designed for use in an asthma nebulizer. This medication can be added to a sinus rinse or used in a more concentrated soak to treat nasal polyps. There is a similar medication available in some countries called Flixonase Nasules.

### Anti-leukotriene medications

Patients with N-ERD produce high levels of inflammatory substances called leukotrienes and these contribute to many of our symptoms. Anti-leukotriene medications like montelukast, zafirlukast and zilueton may be helpful for both asthma and sinus symptoms, however, there are not sufficient trials evaluating their effectiveness in CRSwNP, particularly in the presence of N-ERD, to recommend as an add on treatment to nasal corticosteroids at the current time.

### Aspirin desensitisation

Physician-supervised aspirin desensitisation followed by daily high-dose aspirin is an effective treatment for many N-ERD patients. The maintenance dose that works best for most patients ranges from 650mg to 1300mg aspirin daily. Taking high-dose aspirin can improve sinus and asthma symptoms and slows polyp regrowth after surgery. Aspirin desensitisation appears to have the best outcomes when it closely follows sinus surgery.

Desensitisation **MUST** be undertaken in a healthcare setting – **DO NOT** attempt to do this at home as life threatening reactions to aspirin can occur

### Biologic medications

Biologic medications can be effective for treating both asthma and sinus disease. These medications include omalizumab, mepolizumab, benralizumab, and dupilumab. These are medications that are administered by injection, usually once every 2 to 8 weeks. Due to the cost of the medications, there are limitations on who can receive them, and they may not be available in all countries at the current time, or only offered to very severe cases. Dupixent is already being used to treat nasal polyps in the United States and Europe and it is expected to become more widely available for this indication in the future.

### Coordinating care

One of the biggest challenges faced by N-ERD patients is the need to coordinate care between various specialists. Ideally, we need to be treated by a surgical specialist like an ENT or rhinologist as well as a doctor who specializes in allergy and immunology. Surgical specialists can fully evaluate nasal polyps, remove them, and can provide treatments such as topical steroid rinses. Immunologists typically handle other treatments such as aspirin desensitisation and biologic medications. There are some comprehensive medical centres where your doctors will work together to coordinate your care plan – but this isn't always the case. If your doctors don't seem to be in agreement on your treatment plan, it may be up to you to help get them on the same page. This can be a frustrating experience. When doctors disagree with one another about the best course of action, it can be difficult as a patient to know what to do. This is one reason it's important to be educated on your own disease – it will empower you to speak up for yourself and help guide your own treatment plan.

### Living with N-ERD

#### A life-changing diagnosis

Living with N-ERD can be a challenge. For most of us, coming to terms with the fact that we have a chronic condition is disheartening. Many of us enjoyed good health before developing N-ERD. Many of us are in the prime of our lives enjoying good health when everything suddenly goes downhill. N-ERD is a frustrating disease to manage because it can be difficult to find a doctor who understands the disease and how to treat it. Most of us see several doctors before being diagnosed, and even then, the doctor who diagnoses us may not know the best treatments. Steps to Take; Learn about the disease so that you can be your own advocate. If you haven't been offered helpful treatments, seeing an expert on the disease could make a big difference for you.

#### N-ERD can be dangerous

There is a real risk of life-threatening reactions with N-ERD. It is not uncommon for N-ERD patients to accidentally ingest NSAID containing medications. Many patients are never provided with basic tools such as a list of medications that must be avoided. There are hundreds of over-the-counter medications that contain NSAIDs and it's not always an easy task understanding what medications are safe for us. Patients often face significant anxiety about taking new medications and have a sense that they can't trust their doctor to know what medications are safe for them. This anxiety is not unfounded – research has found that many patients have been prescribed NSAID containing medications by a doctor despite being diagnosed with N-ERD. Due to lack of awareness of N-ERD, doctors who don't specialize in the disease are not always familiar with which medications are safe

for us.

**Steps to Take; Be your own advocate.** Print the list of medications to avoid and provide a copy to every doctor who treats you. Read labels on over-the-counter medications carefully. There is a printable wallet card available that you can carry with you. Having this information easily accessible in an emergency situation could be lifesaving. Printable versions of the medication list and wallet card are available on The Samter's Society website.

#### **Most common medications to avoid**

Aspirin - Excedrin, Alka-Seltzer, Anadin  
Ibuprofen - Motrin, Advil, Brufen  
Naproxen - Aleve, Anaprox  
Salsalate - Amigesic, Salflex, Argesic  
Flurbiprofen - Ansaid  
Ketorolac - Toradol  
Diclofenac - Arthrotec, Voltarol

#### **What pain medications can I take?**

Acetaminophen (paracetamol) is a safer choice for pain relief than aspirin or other NSAIDs, but it can still provoke reactions in some N-ERD patients, particularly when used at high doses. Research has found that 34% of N-ERD patients will have reactions to doses of acetaminophen 1000mg or higher. These reactions are typically milder than reactions to other NSAIDs, but severe reactions have also occurred. If other pain relief options are needed, COX-2 inhibiting medications like Celebrex (celecoxib) are considered safe for N-ERD.

#### **People don't understand**

Having a disease that so few people know about can be isolating. It's a common for N-ERD patients to feel frustrated when trying to explain this disease to others. N-ERD is not an autoimmune disease, but in many ways it is more similar to one than an allergic disorder. Most people who have allergies cannot identify with the intense inflammation that we experience on a daily basis. The name of the disease can confuse people. Many people hear "aspirin exacerbated" and think that as long as aspirin is avoided symptoms should be under control. Every N-ERD patient knows that this isn't the case, but it can be a difficult thing to explain to other people. It's a chronic immune disorder and avoiding aspirin and NSAIDs does not treat it.

**Steps to Take; Having a good support system can make a big difference.** There are support groups for patients such as The Samter's Society, where thousands of patients share their experiences and support one another. Being able to communicate with other patients who understand what you're going through can be life changing. You don't have to struggle with symptoms alone – join the patient community.

It's also important to educate yourself on the disease. The better you understand it yourself, the more empowered you will feel to be able to explain it to other people. Many patients have said that they tell people in their lives that they simply have allergies, because it's easier than trying to explain what N-ERD is. While it might be easier, patients should not feel that they have to hide the fact that they have a serious chronic illness. Explaining the disease to others helps spread awareness and can give the people in your life a better understanding of what you're going through.

#### **Can diet changes help?**

This is one of the most frequently asked questions in our support group. Many patients are eager to learn about ways that they can help control the disease without so many medications. It's important to understand that the disease isn't caused by something you're eating. Many patients go through phases of avoiding various foods in the process of trying to figure out why they are so sick all the time. This can actually be harmful and lead to patients following unnecessarily strict diets in an attempt to avoid anything that may trigger symptoms.

#### **Dietary fatty acid modification**

There is a dietary strategy developed by experts on the disease that may be helpful – it involves reducing omega 6 fatty acids in the diet and increasing omega 3. In our support group, we recommend that patients try this diet before other diets they may read about on the internet. There is an overwhelming amount of information on the internet about various diets that claim to help treat diseases, but this diet was developed by N-ERD experts specifically to address inflammation caused by N-ERD; a small pilot study suggests benefit but more evidence is needed in this area.

#### **N-ERD and alcohol**

Research has found that about 80% of N-ERD patients report sinus or asthma reactions to alcoholic beverages. These reactions can occur with any type of alcohol, but are usually most pronounced with wine and beer. The cause of these reactions is not entirely understood, but experts believe that the high polyphenol content in these beverages may have a similar effect to NSAIDs. Polyphenols are found in red wine, where they come from the grape skin and in beer, where they come from barley and hops. White wine and liquor can also contain polyphenols, derived from the oak barrels in which they are sometimes aged. In general, liquor contains fewer of these substances than wine or beer.

Abstaining from alcohol or reducing your alcohol consumption is likely to have a benefit on symptoms. If you wish to have a drink, you may find that you have less of a reaction to alcoholic beverages that have a lower polyphenol content. Types of alco-

hol that are frequently recommended in our support group include drinks made with vodka or gin, as well as white wines aged in steel containers rather than oak.

Aspirin desensitisation has been found to improve tolerance to alcohol for over 80% of patients.

#### **What about dietary salicylates?**

Decades ago, before much was known about N-ERD, researchers did think that dietary salicylates might be causing N-ERD symptoms. Today much more is understood about the disease and N-ERD experts discourage patients from trying to avoid dietary salicylates.

Inhibition of the COX-1 enzyme is the mechanism by which aspirin and other NSAIDs cause N-ERD reactions. N-ERD experts do not recommend a low salicylate diet because dietary salicylates do not inhibit the COX-1 enzyme like aspirin does. The chemical name for aspirin is acetyl-salicylate (ASA). The chemical structure of ASA is the reason that it inhibits COX-1. It does this by means of the acetyl group attached to its chemical structure. Dietary salicylates have a different chemical structure and therefore do not have the same effect. Therefore, there is no scientific reason why avoiding dietary salicylates would have any benefit. In addition to this, avoiding dietary salicylates may not be healthy. Most fruits and vegetables contain salicylates. Attempts to avoid dietary salicylates may result in nutritional deficiencies.

## 16. Rhinosinusitis during the COVID-19 pandemic

### **Advice related to patients with rhinosinusitis during the COVID-19 pandemic**

COVID-19 has significantly disrupted medical services across the world, and many patients with acute or chronic rhinosinusitis are concerned about the impact of COVID-19 on their treatment. It is a rapidly evolving field, and we offer the following advice based on our understanding at the time of writing.

#### **I think I have acute rhinosinusitis - should I see a doctor?**

In most cases, acute rhinosinusitis does not require medical treatment and it is not necessary to see a doctor, unless any of the red flag symptoms below are present. Furthermore, in many cases, fever and loss of smell may be a sign of COVID-19 and should trigger self-isolation. Telephone advice may be available in many countries if you need further advice.

#### **Should I continue with my regular chronic rhinosinusitis medications during the pandemic?**

If you are already diagnosed with chronic rhinosinusitis, we encourage you to continue with your regular medications. Saline rinses and nasal steroid sprays are available over the counter and you can get repeat prescriptions from your GP. There is no risk related to continued use of topical nasal steroid as they are not absorbed into the body.

If you have non-steroidal exacerbated respiratory disease (N-ERD)/ "Samter's triad" and have been desensitised, you should continue with your daily aspirin treatment.

If you are on a maintenance dose of oral steroids for chronic rhinosinusitis it may be worth discussing if you should continue this treatment with your ENT or respiratory physician.

Patients with chronic rhinosinusitis, including those with nasal polyps, or who have had previous sinus surgery, can have a COVID-19 nasal swab test if required without any increased risk.

Red flags for complications of Acute or Chronic Rhinosinusitis  
We know that many patients are keen to avoid attending hospitals during the pandemic but in these cases any risk of travelling and attending a hospital setting is outweighed by the potential benefits. All hospitals now have strict infection control measures in place to protect patients using their services.

If you have been diagnosed with chronic rhinosinusitis, you should be mindful of the following symptoms:

- severe headache
- swelling and redness around the eyes
- neurological symptoms such as new onset drowsiness, numbness of the cheek, a change in vision or weakness

These may be an indication of complications due to chronic rhinosinusitis and if you experience them then you should seek emergency medical care.

### **Frequently asked questions**

#### **Can I have a nasal swab if I have had sinus surgery?**

*In the first two weeks of your recovery from sinus surgery, it would be better if you could avoid having a nasal swab for COVID-19 as it may be uncomfortable and there may be dissolvable packing inside that would contaminate the swab.*

*Following that initial two week recovery period from sinus surgery, you can have a nasal swab with no additional risk. Although you should tell the person performing the swab, there is no reason to be concerned. If it is a self test kit, make sure you carefully read and follow the instructions attached to your testing swab in order to collect the nasal sample accurately and safely.*

#### **Can I have a nasal swab if I have nasal polyps?**

*You can have still have a nasal swab if you have nasal polyps – although it may be more difficult to insert the swab into your nose it will not cause harm.*

#### **Should I continue to use my nasal sprays if I have been diagnosed with COVID-19 infection?**

*Yes, you can (and should) continue with your regular steroid nasal sprays if you become infected with COVID-19. The level of steroid absorbed into the bloodstream from nasal steroid sprays is very low and does not pose any additional risk during infections.*

*If you know that you have COVID-19, perform your rinsing and apply your sprays away from other household members. If you share bathroom facilities, wipe down surfaces and wash your hands thoroughly afterwards.*

#### **How will I know I have COVID if I have already lost my sense of smell?**

*Early in 2020, it became apparent that many patients with COVID-19 suffered a sudden and significant loss of their sense of smell. In many cases, this is the only symptom that a person may have of COVID-19 infection. It is therefore widely recognised worldwide that if you notice a new, sudden loss of smell or taste then you should consider this a potential sign of COVID-19 infection and should isolate and get a test as soon as possible.*

*Of course, this sudden change may be much more difficult to detect if you are already unable to smell because of your sinus disease. If you still have any limited ability to smell, you should be aware that*



*if this ability suddenly disappears without any change in your other nasal symptoms, then you should consider this is a sign of potential COVID-19 infection and take action as above by isolating and getting tested.*

*If your sinus disease has left you with absolutely no sense of smell then it may be that you would not be able to detect this symptom as a result of COVID-19. Some people have reported a change in sense of taste with COVID-19 infection, although in the majority this is heavily linked to the sense of smell. If you notice a sudden change in your sense of taste however, then you should treat this as you would a loss of smell, and if there has been no change in your other nasal symptoms then consider this as a sign of COVID-19.*

*In all cases, you should be aware of the other symptoms that should prompt isolation and testing – fever and a new, continuous cough – and take precautions as advised by your national government with regards to reducing your risk of infection. Although loss of smell is one of the most common symptoms, most patients do have other symptoms before, at the same time, or shortly after loss of smell, including cough, fever, muscle aches, tiredness, sore throat, red-eye, tummy upset or skin rashes.*

#### **Advice related to patients with loss of sense of smell during the COVID-19 pandemic**

*Loss of sense of smell is one of the most common symptoms of COVID-19 infection and for many it may be the only symptom. The loss is typically sudden and severe, but may also be partial, or associated with smell alteration. Any new change in your sense of smell during the pandemic should prompt self-isolation and testing.*

*If you are known to have chronic rhinosinusitis and suddenly lose your sense of smell you should consider whether you are also experiencing a simultaneous worsening in nasal blockage. If you are not and the loss of smell occurs in isolation, you should consider whether you may be infected with COVID-19.*

*For many people, the loss of smell and taste associated with COVID-*

*19 is short lived and improves within 2 – 4 weeks. There is no need for any specific treatment during this time.*

*The duration of loss of smell and taste is not related to being infectious and so you should follow the current guidance with regards to self-isolation.*

*Smell training is an effective treatment and should be considered by anyone with smell loss lasting for more than 4 weeks.*

*Some patients who have lost their sense of smell from COVID-19 report a period of smell and taste disturbance or 'parosmia'. This can make many foods or smells unpleasant. It is a sign of recovery but may last for weeks or months. Coffee, meat, onion and peanuts are common triggers but it can be different for everyone. Try to modify recipes. Cinnamon flavoured gum and toothpaste can be helpful. Please see the links below for further advice.*

*Losing your sense of smell and taste can have a huge impact on your quality of life. It can be difficult to access support and it can be hard for friends and family to understand how it affects you if they have not experienced it themselves. We have worked with two patient groups to provide resources to help and allow you to share experiences with others who have been affected.*

There are sections on smell training, advice sheets, and lots of further information.

<https://abscent.org/nosewell>

Fifth Sense – smell training

*If you have smell loss for more than 3 months, your primary care doctor may refer you to ENT to exclude other causes of smell loss, such as nasal polyps, particularly if you have ongoing nasal obstruction. Unfortunately, there are no tests that can predict whether you will regain your sense of smell, but we have good data that shows that a very large proportion of patients will recover, and that recovery can still occur many months after the initial infection.*

## 17. EPOS Patient resources and websites

### Where to find the EPOS 2020 guideline

A full range of patient information leaflets, including translations are available <https://www.europeanrhinologicsociety.org>

To read the full guideline or the summary you can visit the website <https://epos2020.eu/>. There you can also find interesting webinars about EPOS 2020, for example “EPOS 2020: Everything you need to know”. You can also read about the development of the EPOS 2020 guideline in the online published development report. In case you do not speak English, the summary of the EPOS guideline is also available in Polish, Portuguese and Chinese on this website.

### Where to find good-quality information about my chronic respiratory disease

The European Forum for Research and Education in Allergy and Airway diseases (EUFOREA) is an international non-profit organization with a vision and mission towards prevention of allergy, asthma and chronic rhinosinusitis and reducing the burden of these diseases. It has a patient platform with information about chronic rhinosinusitis, allergy and asthma. Educative and easy understandable information can be found about a disease in general, about any symptoms, medical or surgical treatments available, expectations of treatments and follow-up of disease. There are also numerous FAQs from patients with answers provided by experts in the field. You can find all this information at <https://www.euforea.eu/patient-platform>.

You have complaints of your sinuses, but you do not know if it could be chronic rhinosinusitis or maybe an allergy. Do the quick test!

There is an online questionnaire developed to see if your symptoms might be related to a chronic respiratory disease such as chronic rhinosinusitis or allergic rhinitis. The test is not meant to provide you with a clear diagnosis and it does not give medical advice. So if your symptoms are bothersome you should always visit your doctor. You can start the test here: <https://www.euforea.eu/chronic-sinusitis-assessment>.

Mobile application (e-diary) for Chronic Rhinosinusitis mySinusitisCoach (Galenus Health App) has been developed to provide an e-tool for you as a patient. Simply record how you feel, set an alert for taking medication and find out how effective your treatment is. You can also share it with your doctor so that he/she has an overview of your disease state and effect of the treatment. Simply download the app in the Google Play



Store or Apple store. More information about the application can also be found at <https://www.galenushealthcompass.com>.

### Mobile application (e-diary) for allergy and asthma

MASK-Air is developed to provide an e- tool for you as a patient. You can simply record daily symptoms, the way you feel and the application can assist you in taking your medication and show how effective treatment is. You can also share it with your doctor so that he/she has an overview of your disease state and can see what is the best treatment for you. Simply download the app in the Google Play Store or Apple store. More information about the application can also be found at <https://www.mask-air.com>.



Patient Advisory Board for patients with Chronic Rhinosinusitis  
Many countries have their own patient advisory boards – your ENT specialist should be able to help advise on this.  
To give you a voice as a patient with chronic rhinosinusitis there is a Patient Advisory Board as part of the European Forum for Research and Education in Allergy and Airway diseases.  
The board investigates the most important needs of patients, investigates the impact of disease on patients and a society and participates in discussions on a political level. Interested to join?  
You can send an email to: [contact@euforea.eu](mailto:contact@euforea.eu). More information can be found at <https://www.euforea.eu/patient>.

### The Samter's Society resources & support for AERD

A special interests group for patients affected by Aspirin Exacerbated Respiratory Disease (AERD). On the website (visit: <https://www.samterssociety.org>) you will find information about

the disease itself, treatment options and we help you to find a specialist in the field. You are also able to connect with thousands of other patients through our AERD- Samter's Triad support group on facebook. Share your experiences!

#### **Fifth Sense**

A membership organization for patients with smell- and taste-related disorders that provides support and advice to anyone suffering from a related disorder or to parents of children with a smell- or taste- related disorder. You will find information about how smell and taste actually work, diagnosing and treating related disorders and where to find a clinic that treat smell and taste disorders. All information can be found at : <https://www.fifthsense.org>.

[fifthsense.org](https://www.fifthsense.org).

#### **AbScent**

AbScent is a charity to support those with smell disorders and their families. They offer information and practical advice across multiple platforms, with peer support being central to their services. They have several channels for this, including a webinar series with leaders in the field of rhinology, psychology and other related disciplines, the free Snif smell training app, and the AbScent Network where courses are offered. The charity offers an opportunity to engage closely with their own research projects as well as access to outside research initiatives. For more information, please visit <https://www.abscent.org> .

## 18. Frequently asked questions about EPOS

The following section is written with the help of patients involved in the development of the EPOS2020 guidelines to help explain what the guidelines mean for patients.

### **What does EPOS stand for?**

*EPOS stands for the European Position paper On Rhino-Sinusitis, covering the diagnosis and management of both acute and chronic rhinosinusitis in primary (community-based) and secondary (hospital-based) care.*

### **What are the EPOS 2020 guidelines?**

*The guidelines are a summary of the most up to date information regarding the treatment and management of rhinosinusitis and nasal polyposis.*

The first EPOS guidelines were developed in 2005 and have subsequently been updated in 2007, 2012 and now 2020. In essence, the guidelines are a summary of the very latest thinking in rhinosinusitis and nasal polyposis. To develop the guidelines, academic and clinical leaders in this field, along with the help of some patients, looked at all the information available in this area, from as far back as 1960 through to the present day, and summarised the most important elements.

The guide represents what all those experts agree should be recommended practice at this current time.

### **Why are guidelines like EPOS necessary?**

*To ensure that everyone who is in any way connected to the treatment or management of rhinosinusitis and nasal polyposis has the best information available.*

The field of medicine is constantly changing. The continual emergence of new research and improved practices means it is important from time to time, to take stock of these developments and ensure that current clinical practice reflects the latest thinking.

This process happens in all areas of medicine from heart disease to child health and it is vital to ensure everyone around the world has access to the best information available.

To provide the best of healthcare, treatment should ideally be based on evidence-based medicine. When a treatment is evidence-based, this means that several scientific trials have evaluated its' effect in a certain patient population. With help

of these study results, a doctor can make a recommendation in favor of using a certain treatment that has been shown to be of benefit or advise against a certain treatment that does not work or causes harm. The results of scientific trials cannot always be perfectly applied to any given individual, and doctors will use their experience and judgement to try to make recommendations that are personalised to their patient. EPOS aims to look at all the evidence available and summarise it in a form that is easy to use and understand by doctors and healthcare workers in this field.

Unfortunately, scientific trials are often expensive and difficult to perform. This is because whenever patients are enrolled in trials, their health and safety are absolutely paramount and there are limits to what they can be asked to do. Therefore, for some treatments, there are no large studies available. In that case, experts from all over the world come together and form a shared-opinion of what is the best of healthcare in these situations.

### **What is the objective of the EPOS2020 Guidelines**

*It is primarily to provide management strategies for rhinosinusitis based on relevant research.*

Beyond this, there are many things that the EPOS2020 guidelines hope to achieve. The guidelines aim to:

- Provide healthcare professionals with a summary of the best methods for diagnosing and managing patients in both the hospital and the wider community setting
- Inspire researchers to further study acute rhinosinusitis and chronic rhinosinusitis
- Support the use of standard definitions and measurements of the disease
- Hopefully reduce unnecessary (antibiotic) treatment
- Encourage people to form new collaborations to answer unmet research questions

### **Who will use the EPOS2020 Guidelines?**

*Many individuals and groups from doctors through to government bodies.*

EPOS2020 will provide guidance for relevant government bodies, national and international drug agencies [e.g. the European Medicines Agency (EMA) and the Food and the Drug Administration (FDA) in the USA] and scientific societies, particularly regarding the use of terminology, definitions and classifications for clinical trials. Most importantly it will be used by

doctors treating patients with sinus disease to help ensure that all patients are offered evidence-based care.

#### **Who writes EPOS?**

*An international group of experts who are leaders in the field of rhinosinusitis and nasal polyps.*

It took approximately 18 months and around 80 people from over 20 different countries to review all the latest information and then write and publish these guidelines.

This group consisted of renowned experts including:

- Ear, Nose and Throat Surgeons
- Allergists
- Pharmacists
- Microbiologists
- General Practitioners
- Paediatricians
- Pulmonologists
- Neurologist

There were also patients involved in the guidelines to ensure the recommendations were always seen from a patient's perspective. EPOS2020 is also supported by professional organisations, such as the European Rhinologic Society (ERS) and the European Academy of Allergy and Clinical Immunology (EAACI).

#### **Is this just for use in Europe?**

*No, EPOS2020 will have relevance around the world.*

Although EPOS has the word European in its title, and a strong European representation among the people who developed it, it is intended to be used beyond Europe. Individuals from all over the world have contributed to the development of these guidelines and they will have relevance in many countries outside of Europe.

#### **Is EPOS the only guideline on ARS/CRS?**

*No, there are several guidelines on rhinosinusitis.*

Some of these guidelines reflect the different treatments available within healthcare systems; others will represent the opinion of experts assembled from a particular continent or group. EPOS was the result of many meetings and discussions between experts from all over the world, with the goal of ensuring that the guideline represented as wide a range of experience and evidence as possible.

Ultimately, the global society of surgeon-scientists are in constant communication with each other to share new evidence and best practice. This helps to develop more or less uniform guidelines all over the world with minimal differences between existing guidelines.

#### **Can I find patient relevant information in the EPOS guidelines or is EPOS written for physicians only?**

*No, EPOS is certainly not written for exclusively for doctors to read.* However, reading EPOS guidelines, patients are faced with certain medical language that is not always easy to understand. This scientific language is used because sometimes there is a universally understood and agreed term that is precise and widely understood. For example, anatomical terms are instantly recognisable to doctors; but clearly this is only with the benefit of many years of scientific training.

That is why we have published this series of separate leaflets of patient information on all the topics of EPOS guidelines. The aim of these leaflets is to distil the same evidence, experience, and advice as the central guideline but in language which can be understood by members of the public.

#### **My doctor suggests another treatment plan than I can find in the EPOS guidelines. Should I be worried?**

*No, there may be many reasons that this can happen.*

Firstly, the EPOS guidelines are just that – for guidance, and not an obligation to follow. Secondly, it is possible that your physician makes a different decision based on several factors in your specific individual situation and their own experience. Every medical situation and patient is different, so it is impossible for a guideline to cover all these situations.

Of course, you can always share the information you have read in the EPOS guideline with your doctor and ask about the individual circumstances that mean your treatment plan has diverged from EPOS.

#### **Some treatment recommendations in EPOS guidelines seem unclear. How should I deal with that?**

*As mentioned above, scientific trials are difficult to plan and perform and often there is no large scale results available for certain treatments.*

Sometimes a treatment option is not studied at all or only within small studies with limitations in its usefulness.

In that case, EPOS can make a recommendation based on expert opinion. And furthermore, there is always room within guidance for individual healthcare providers to apply their own interpretation and experience for the benefit of their patients.

#### **Is it possible that EPOS recommendations will change with time?**

*Yes, in fact it is even the most likely thing that will happen!*

It is only a good thing that scientific evidence and knowledge keeps on growing and developing. But this also means that a recommendation that was written in one guideline may seem outdated over time as new trials become available. This happens in all fields of medicine and science. Updates of EPOS guidelines are planned every 5 to 10 years to address the new scientific evidence. When writing a guideline, there may be a sense amongst

the experts that a new development is on the horizon but is not yet clear enough to be included. In these circumstances, there is often a deliberate effort to include questions that are left open or unanswered. By the time the next guideline is written, of course the hope is that we will be able to answer these questions!

## 19. Glossary – Common medical terms used in relation to sinus disease

**Acute rhinosinusitis** – short-lived (less than 12 weeks) infection or inflammation of the nose and sinuses, which is usually caused by viral infection, and less commonly a bacterial infection

**Allergy** - Immune response resulting from exposure to a trigger “allergen” in a sensitised individual

**Allergic rhinitis** – Immune reaction occurring in the nasal cavity caused by breathing in air-borne allergens, such as pollen, which result in localised symptoms such as itching, sneezing, nasal congestion and nasal discharge

**Allergic fungal rhinosinusitis** – Subtype of chronic rhinosinusitis caused by allergic reaction to fungal allergens that causes nasal polyps and sinus inflammation, which often requires surgery and has a higher risk of recurrence to other subtypes. Sometimes abbreviated to “AFRS”

**Antibiotics** – Medical treatment that is directed against bacterial infection. Antibiotics are of little value in the majority of cases of acute rhinosinusitis which are caused by viral infection, but may be used in cases of bacterial acute rhinosinusitis, acute exacerbations of chronic rhinosinusitis, and used also for their anti-inflammatory effects in chronic rhinosinusitis at a lower dose but over longer courses. Usually given by mouth but can also be used in the nose as a cream or added to saline washes in some cases

**Antihistamines** – Medical treatment that blocks the allergic response, which can be given as tablets or nasal spray. Not commonly used in the treatment of rhinosinusitis unless the patient has co-existing allergic rhinitis

**Anosmia** – complete loss of sense of smell; more commonly found in association with nasal polyps but may be a feature of all types of sinusitis. Partial loss of smell is described as hyposmia

**Balloon sinus dilation** – minimally invasive technique that may be used to stretch the opening of the maxillary, frontal or sphenoid sinuses in selected patients with sinus disease resistant to medical treatment. Sometimes referred to as “balloon sinuplasty”

**Biologic therapy** – Relatively new treatment, usually given by

injection that specifically blocks unwanted parts of the immune response (using monoclonal antibodies). Used in patients with asthma, and/or chronic rhinosinusitis with nasal polyps, who have Type 2 inflammation

**Chronic Rhinosinusitis (CRS)** – long lasting (more than 12 weeks) infection or inflammation of the nasal cavity. May be due to disease within the nose (primary) or much less commonly occur as part of multisystem diseases (such as cystic fibrosis or immune deficiency) or dental infections (secondary). CRS affects up to 10% of the adult population and causes symptoms such as nasal obstruction, discharge, facial pain and /or loss of smell

**Corticosteroids** – Medical treatment that reduces the unwanted immune response that causes inflammation in the nose. May be given as nasal treatment or by mouth. Nasal treatment is much safer and can usually be used long-term, when given by mouth there is a much higher risk of side effects which limits how often treatment can be used

**Controlled disease** – a disease state where the patient does not suffer sufficient symptoms to impact on their quality of life, from either the disease itself or the treatments given

**CT Scan** – A series of X-rays that gives detailed information on the extent of sinus disease and anatomy, usually used when considering patients for surgery or when there is uncertainty regarding diagnosis in order to minimise associated radiation exposure

**Decongestants** - drugs that help relieve nasal obstruction. They work by reducing blood flow to the nose and should only be used for short periods, as they can cause rebound congestion. Ideally use should be limited to less than 5 days and never more than 10 days

**Deviated septum** – A bend or displacement of the anatomic structure in the nose which divides the nose into left and right sides; mild deviations are common place and usually asymptomatic while severe deviations may prevent sinus medications entering the nose or prevent access during sinus surgery and may sometimes need to be corrected

**Draf 3/ Frontal Drill Out / Modified Lothrop Procedure** – Extended endoscopic surgery to the frontal sinuses when bone

separating the two sides is removed to make a larger, common drainage pathway

**Endoscope** – Small telescope used to examine the nasal cavity and openings of the sinuses

**Endoscopic Sinus Surgery** – sinus surgery performed through the nostrils using the endoscope to view the anatomy

**Endotype** – features of a disease state that help to determine the disease course, severity and response to treatment, like a disease footprint. Typically needs samples to be taken from the blood, mucus or nasal lining

**Eosinophilic sinusitis** – subtype of chronic rhinosinusitis with features of type 2 inflammation that typically causes widespread polyps and disease that responds well to steroids

**Exacerbation** – Symptom flare up, which may be caused by infection

**Ethmoid sinus** – paired sinuses that are found between the eyes, formed from several small sinus compartments like a honeycomb, sitting between the eye and the skull base

**Frontal sinus** – usually paired sinuses found in the forehead, although one or both may be undeveloped

**Functional Endoscopic Sinus Surgery** – Name used to describe sinus surgery performed through the nostrils using the endoscope to view the anatomy, where surgery is targeted to open and restore normal function to the common sinus drainage pathway (the ostiomeatal complex) but often used more widely to describe all endoscopic surgery. Although many surgeons use the term “FESS” and “ESS” interchangeably, many experts are moving towards preferring the term “ESS” as a broad descriptor of sinus surgery

**Immunotherapy** - treatment that involves the stimulation or suppression of functions of the immune system. Most commonly used in relation to allergy, where repeated exposure to small amounts of allergen can desensitise the immune response

**Maxillary sinus** – Paired sinuses found in the cheeks, sitting close to the dental roots and the eye

**Mucosa** – lining of the nasal and sinus cavities, which can become swollen in the setting of infection or inflammation

**Nasal polyps** – inflammatory, grape-like outgrowths of the sinus lining; usually bilateral

**Postnasal drip** – Mucus discharge that is felt at the back of the nose and into the throat

**Packing** – Material placed in the nose to reduce bleeding after surgery (or in the setting of nosebleeds not related to surgery, which may break down by themselves without needing to be removed (absorbable) or may need to be removed. Your doctor will advise you if you are having packing and if it needs to be removed

**Paediatric** – referring to infant, children and adolescents under the age of 18

**Phenotype** – subgroup of disease based on observable differences – in CRS, this described subgroups of with or without nasal polyps. It is helpful to guide treatment, but separating groups by endotype (biological footprint) is likely to better predict disease course and response to treatment

**Polypectomy** - surgery to remove polyps from the nasal cavity that may be combined with surgery to the sinuses or performed on its own

**Rhinitis** - Irritation and inflammation of the lining of the nasal cavities. Rhinitis is associated with symptoms such as alternating nasal congestion, runny nose, and postnasal drip.

**Recurrence** – return of symptoms after period of improvement which requires further medical or surgical treatment

**Refractory** - difficult to cure, or does not respond to treatment

**Saline irrigation or rinsing / sinus washing (sometimes also called douching)** - rinsing the nose and sinus cavities with salt-water solution to help remove irritants and mucus from the nose. May be performed with small or large volumes, and using equipment such as netipots, squeeze bottles or powered irrigation machines

**Splints / stents** - removable or absorbable ‘spacers’ used to prevent or reduce scarring, or to deliver steroids to the sinus cavity

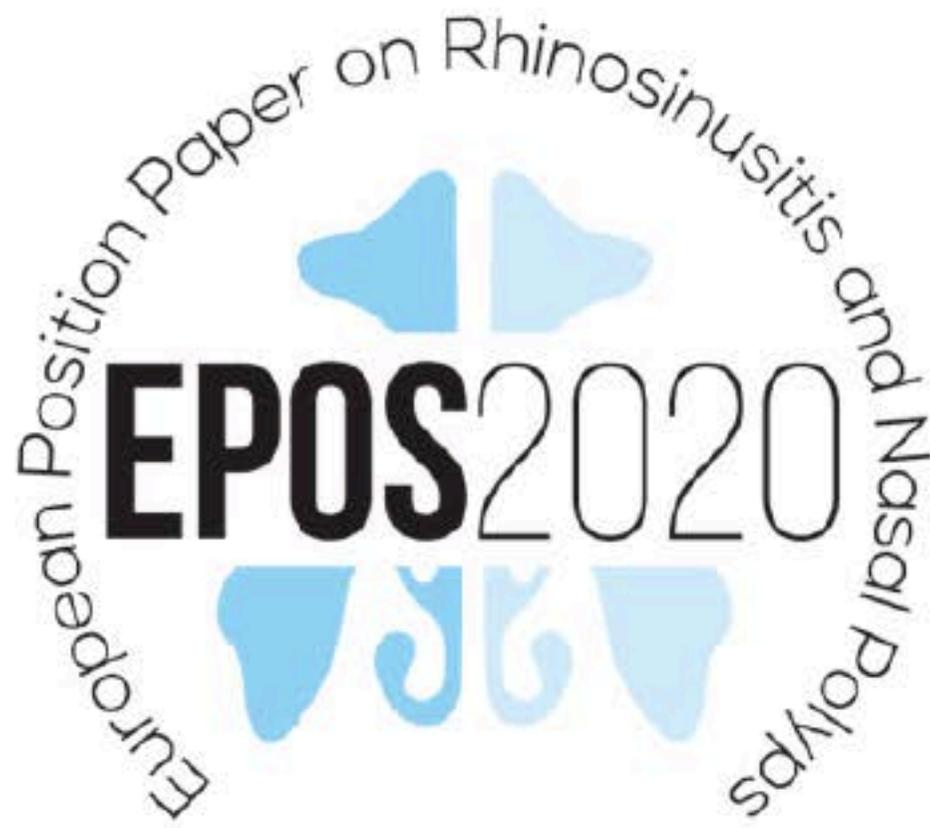
**Sphenoid sinus** – paired sinuses found at the back of the nasal cavity

**Turbinates** - bony structures that extend from the side wall of each nasal cavity. There is a set of inferior, middle, and superior turbinates in each side. Like the nose, the turbinates are lined with mucosa which can swell and decongest during the nasal cycle. Sometimes, the turbinates become swollen due to rhinitis and may be seen at the nostril when they may be mistaken for



a polyp

**Uncontrolled disease** – Persistent symptoms and evidence of ongoing disease activity, impacting on quality of life which is usually an indication to change or increase treatment



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### Position paper

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