



Incorporating the Australian Centre for Hyperhidrosis & Facial Blushing

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ETS Surgery for Severe Craniofacial Hyperhidrosis Detailed Information for Prospective Patients.

The following is a detailed account of the effects, complications and side-effects of ETS surgery for severe sweating of face and scalp (craniofacial hyperhidrosis). It is based on both our own experience and experience and scientific information gained at the meeting of the International Society for Sympathetic Surgery held at Erlangen, Germany, in May 2003.

If you are seriously contemplating ETS surgery for craniofacial sweating you must read and familiarise yourself with the following information. This document should be read in conjunction with the more general information provided on our web site at www.lapsurgeryaustralia.com.au. Before proceeding with the operation you must make sure that you understand the entire document and if not that you clarify any issues with your surgeon BEFORE the operation. You will have the opportunity to ask questions of your surgeon and you are encouraged to research both your sweating condition and the treatment options prior to your first consultation. You will be asked to sign a consent form acknowledging that you have read and understood this document and to initial each page of this document to confirm that you have read it.

The Cause of Craniofacial Hyperhidrosis.

The exact cause is unknown, but it is now classified as a disease of the autonomic (involuntary) nervous system. There is evidence that it is a genetic condition (autosomal dominant with variable penetration) with up to 50% of people affected having a family history of craniofacial hyperhidrosis, severe facial blushing or one of the other sweating syndromes (armpit or hands).

There is no evidence that it is a primary psychological condition although there can be psychological *consequences* from the condition.

Who Should Have the ETS Operation for Severe Craniofacial Sweating?

Surgery for any condition should always be the last resort. Blocking the sympathetic nerves will, for the majority of people with severe craniofacial sweating, provide a significant improvement in quality of life. This assumes that your condition is a major impediment to your lifestyle. With any surgery, complications can occur even though they may be unusual.

Side-effects with ETS surgery can occur and a small minority of people, less than 5% in most published studies, will regret having had the operation. For around 90% of people who have the surgery for the right reason, the result will be a significant improvement in quality of life.

Before considering ETS surgery we recommend, if you have not already done so, that you attend your family doctor for a thorough medical examination looking for any other cause of the abnormal sweating. Other possible causes include an overactive thyroid gland and certain other diseases of the endocrine system. If you are overweight, especially if your BMI (body mass index) is greater than 30 - see our web page on Lap-Band® for a BMI calculator – we strongly recommend weight loss before deciding whether to go ahead with the surgery or not.

Are There Any Alternatives to Surgery?

A variety of non-surgical treatments have been suggested and tried for severe craniofacial sweating. These include medications such as beta blockers, Ditropan and other anticholinergics, Botox and a variety of psychological and alternative treatments. Although some individuals may be helped, the majority will gain no significant or lasting benefit from these non-surgical treatments. Botox treatment may give temporary relief for a few months although Botox injections on the face and scalp may be quite unpleasant. The only treatment which is known scientifically to work longterm for severe craniofacial sweating is ETS surgery. Nonetheless we recommend that you try some or all of these non-surgical treatments before going ahead with ETS surgery, especially weight loss if appropriate.

The ETS Operation for Severe Craniofacial Sweating.

As discussed at the fifth meeting of the International Society for Sympathetic Surgery in May 2003, there is no consensus on the best ETS operation for craniofacial sweating.

The commonest operation is cutting or clipping the sympathetic chain at the level of the second rib. This has very high cure rate for severe craniofacial sweating; however there is a small risk of severe compensatory hyperhidrosis. (See later in this document for an explanation of compensatory sweating.)

Many surgeons, including us, are now suggesting to our patients that blocking the sympathetic nerves at a lower level, on the third rib, will give nearly as good a result as the higher blockade, but with a lesser chance of developing severe compensatory hyperhidrosis. In other words we offer a trade off for the face and scalp retaining some sweating against reducing the possibility of severe side effects from the operation. This will be discussed carefully with you prior to the operation.

The effects, complications and side-effects of this procedure are discussed later in this document. We now EXCLUSIVELY perform clipping of the nerve rather than cutting the nerve because of the small risk of severe compensatory sweating.

Clipping the nerve is just as effective as cutting it in terms of achieving the desired effect, but clipping offers the THEORETICAL chance of reversal in the event of severe compensatory sweating. It must be emphasised that although there are individual reports of successful reversal of the operation by removing the clips, there is as yet no scientific evidence that reversal is possible by removing the clips.

We cannot guarantee reversal of the operation in the event of severe compensatory sweating or other undesired outcome.

The Kuntz Nerve.

If you research the topic of ETS, you will come across various claims and counter-claims about the importance or otherwise of the Kuntz nerve. The Kuntz nerve is a small nerve fibre sometimes seen on the second rib not far from the main sympathetic chain. Its function is not known in humans. At the meeting of the International Society for Sympathetic Surgery in Germany, May 2003, attended by a majority of the world's experts in ETS surgery (including us), *all but one of the surgeons present were of the opinion that the Kuntz nerve played no part in the success or failure of ETS surgery. We share this majority opinion.*

Effects.

Effects are the intended outcomes of the ETS operation. For craniofacial sweating, around 90% of patients will experience either total cessation of sweating or a marked decrease in sweating so as to produce a significant increase in quality of life. In very rare instances the operation is either not successful or sweating recurs at a later time. In this instance we can offer a re-operation with clipping of the nerve at the level of the second rib if this was not done at the first operation. This will stop the sweating in almost 100% of people, but will increase the risk of severe compensatory sweating.

Complications.

Complications are unintended outcomes of the operation itself.

Examples of complications include BUT ARE NOT LIMITED TO the following:

Death. We are aware of nine deaths worldwide from this procedure. To the best of our knowledge, all of these deaths occurred with surgeons or institutions that were unfamiliar or inexperienced with the ETS procedure.

Bleeding. Bleeding can be a complication of any surgery. The chest cavity, in which the sympathetic chain is situated, contains very large blood vessels which if damaged accidentally during surgery could cause catastrophic bleeding. It is probable that most or all of the deaths reported from ETS surgery were due to bleeding. In experienced craniofacials the risk of major bleeding is extremely low. In our experience of over 500 ETS operations there have been no cases of major bleeding. Results published by the major centres performing ETS surgery confirm that the incidence of severe bleeding is extraordinarily low.

Lung problems. In order to get access to the sympathetic nerves in the chest it is necessary to collapse the lung. At the end of the procedure the lung must be re-expanded and all of the gas removed from the chest cavity. Sometimes the lung does not expand completely and some gas is left inside the chest cavity. This is called a pneumothorax. In most cases this is of no major concern but if the pneumothorax is large a chest tube must be inserted. In even more unusual circumstances there may be a leak of air from the lung requiring the tube to remain in place for one or more days.

A more serious lung problem may be encountered during the surgery if adhesions of the lung to the chest wall are present. Adhesions occur commonly in smokers or in people who have had serious infections of the lung in the past. Often we can deal with these adhesions and still perform the sympathectomy but the risk of bleeding and lung complications after the surgery are increased. These complications can usually be dealt with by a tube into the chest which may require being present for several days.

On occasions the lung adhesions may be sufficiently severe to cause the operation to be aborted. *The decision to abort the operation is at the surgeon's absolute discretion.* It cannot be predicted preoperatively.

Horner's syndrome. Horner's syndrome is caused by damage to the stellate ganglion. The stellate ganglion is part of the sympathetic chain situated above the second rib. This is now very rare in the ETS operation for craniofacial sweating when the nerve is clipped at the level of the third rib, well away from the stellate ganglion. The chance of interfering with the stellate ganglion is therefore remote. When the nerve is clipped the level of the second rib there is a slightly higher risk of Horner's syndrome, but the risk remains very low.

The most obvious sign of Horner's syndrome is a droopy eyelid. Less obvious is constriction of the pupil, a slight sinking of the eyeball and some redness of the white part of the eyes.

Horner's syndrome is uncommon with modern ETS techniques and when it does occur it is usually temporary. Nonetheless, there are recorded instances of Horner's syndrome being permanent. This does not affect eyesight and the droopy eyelid can be fixed by plastic surgery. However, constriction of the pupil, some redness of the whites of the eye and slight recession of the eyeball would be permanent.

Anaesthetic Complications. Modern anaesthesia is extremely safe but in rare instances complications can occur. In some centres it is recommended that only one side of the sympathectomy is done at the one operation, the second being done some weeks later. There have been reports of fluid on the lungs (pulmonary oedema) in association with anaesthesia for operations on both sympathetic chains at the one operation. Our own experience and that of all of the major centres performing sympathectomy is that this complication is so rare that there can be no justification for performing two separate operations to complete the sympathectomy.

Post-operative Pain. It is common to have some vague pain in the centre of the chest following ETS. A few patients may experience pain along the inner aspect of the arm. This is usually related to trauma to the lower nerve plexus to the arm and in very instances may be permanent.

Nerve Damage. Damage to the nerves between the ribs (intercostal nerves) can occur occasionally. Nerve damage presents as a dull pain or numbness in the inside of the arm or along the route of the rib. In nearly all cases this is temporary and returns to normal within a few weeks or months. The cause of this is bruising to the nerves during the operation. Very rarely this may be a permanent problem. However it will not affect movement or function of the upper limb.

Rare complications. There are a myriad of complications of any operation about which entire textbooks have been written. It is impossible to detail all possible complications in this document. The prospective patient is again warned that unexpected and unpredictable outcomes can and do occasionally occur after any surgery.

Side-effects Known to Be Associated with Sympathectomy.

Side-effects are direct consequences of the operation other than those intended. Side-effects can vary from being beneficial to being very serious.

Compensatory or Reflex Sweating. This is the most common and potentially the most serious of the known side-effects of ETS surgery for severe craniofacial hyperhidrosis. ETS surgery, as well as stopping the sweating on the head and scalp, will stop nearly all sweating on the hands. For reasons that we do not fully understand, almost all patients will experience some increased sweating in other areas of the body, principally on the chest, back, groins and thighs. The increased sweating can vary from almost nothing through to an annoyance but in a small percentage of cases, less than 5% in most studies, the increased sweating may cause as much or more distress than the original craniofacial sweating problem. There is some evidence that compensatory sweating is more likely to be a problem in males, people who are overweight and those who have a tendency to excessive sweating elsewhere on the body prior to the operation. There is no sure way to predict who will or who will not have a problem with compensatory sweating.

Compensatory sweating tends to be worse in the first few months after the operation and during the first summer after the operation. There is a tendency for it to improve in the 12 to 18 months following surgery but any changes after this are likely to be permanent.

Mild to moderate degrees of compensatory sweating can be improved with the use of anticholinergic drugs such as Ditropan although side-effects such as a dry mouth may limit the effectiveness of these drugs. Botox may be useful if sweating is confined to a particular area that is not too large.

In the unfortunate event of severe compensatory sweating we advocate removal of the clips, preferably in the first 30 to 60 days after the operation is performed. We again emphasise that although there are reports of reversal of compensatory sweating by removal of clips, this has not been confirmed scientifically.

There are also reports of successful reversal of ETS by nerve grafting but likewise there is no scientific proof that nerve grafting can reverse the ETS operation. There are only a very few surgeons in the world who have attempted this procedure and none in Australia.

IF YOU PROCEED WITH THE ETS OPERATION FOR SEVERE CRANIOFACIAL SWEATING YOU ACCEPT THE SMALL POSSIBILITY OF DEVELOPING SEVERE COMPENSATORY SWEATING WHICH MAY NOT BE ABLE TO BE REVERSED.

Gustatory Sweating. Gustatory Sweating is excessive sweating on the temporal region of the face stimulated by the smell or taste of food and drink. This is a very unusual syndrome and the exact cause of this following ETS is not known. It is classed as a side effect of ETS surgery. It occurs in less than 10% of patients undergoing ETS for craniofacial sweating and is usually a minor irritation.

Sometimes an application of Robinul gel to the affected area prior to meal times may be of help. Botox may also help.

If the gustatory sweating is severe then removal of the clips may be necessary. Once again there is no scientific evidence that this will reverse the side effect but there is some anecdotal evidence that it is worth trying in severe cases.

Dry Hands. Your hands may be completely dry after the ETS procedure. This can sometimes cause difficulties with handling paper and may require regular use of moisturising creams or lotions.

As discussed earlier in this document, clipping the nerve lower down on the sympathetic trunk may allow some ongoing sweating of the palms which may even be preferable to the dryness caused by the higher level clipping.

Initially your hands will be very warm but this effect usually wears off after about six months and some people paradoxically develop cold hands at a later date.

Changes to the Heart and Circulation. Sympathectomy causes changes to the heart and circulation which are well documented. The heart rate is slowed but the heart compensates by pumping slightly more blood with each heart beat. The maximum heart rate in exercise is decreased but for most people there is no change in physical capacity. There is anecdotal evidence that very high performing athletes may suffer a small decrease in maximum physical capacity and if you are an elite athlete you should discuss this very carefully with your surgeon.

Minor changes to blood pressure can occur but these tend, if of any significance at all, to be of more benefit than harm.

Very rare reports have been made of recurrent episodes of fainting after ETS. Whilst probably related to the sympathectomy, the exact cause is not known.

Sweating of the Feet. We know of no reason why sympathectomy at the T2 level should affect foot sweating. Nonetheless, some people report increased sweating, some report decreased sweating and others see no change in sweating of the feet.

Prickling Sensations on Scalp. Some patients notice an unpleasant prickling sensation on the scalp after eating, particularly spicy meals.

Side-effects Reported but Not Known to Be Related to Sympathectomy.

A huge variety of symptoms have been ascribed to the sympathectomy by patients, particularly those who have not had a good result or who have other side-effects of the procedure.

These include symptoms such as loss of libido, tiredness, hair loss, funny feeling in the chest, pains in various parts of the body and many other unexpected symptoms.

Whilst we cannot entirely exclude that these symptoms may be due to the sympathectomy, we believe that most of these symptoms are incidental or psychological as there is no known physiological relationship between the sympathectomy and the symptoms reported.

Summary.

ETS surgery for craniofacial sweating must always be considered a last resort and only undertaken when the craniofacial sweating is causing severe decrease in quality of life. For the majority of patients who undertake the operation there will be a significant improvement in quality of life. In very rare instances the operation will not be effective. In undergoing the operation you accept a small risk that you will end up with side-effects which may be as severe as or even more severe than the original craniofacial sweating problem.

Complications, however uncommon, may also occur and these are an inherent risk of surgery.

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