

## What is Idiopathic Intracranial Hypertension?

Idiopathic Intracranial Hypertension (IIH) is a condition where the cerebrospinal fluid (CSF) builds up around the brain. IIH has been known by other names such as Benign Intracranial Hypertension or Pseudotumour Cerebri. It is a condition with an unknown cause or causes.

When the brain pressure is high, the majority of people will have eye (optic) nerve swelling called papilloedema. There is a rare type of IIH where there is no papilloedema called Idiopathic Intracranial Hypertension without papilloedema (IIHWOP). See IIHWOP information leaflet.

### **What is a venous sinus stent?**

A stent is a small piece of metallic mesh tubing. It is used in various areas of medicine to treat blood vessels that are too narrow for blood to flow. The stent opens up the middle of the blood vessel (also called a lumen) by supporting the walls of the blood vessel.

The venous sinuses are a network of veins that drain blood from the brain to eventually return it to the heart for re-circulation. When a stent is placed inside one of the veins that form this network, it is known as a venous sinus stent (VSS).

### **Why are stents used in IIH?**

Doctors have considered that stents may help in IIH, as they noticed that the veins can be compressed, called a stenosis, by the high brain pressure in some people

with active IIH. By putting a stent in a narrowed area of the vein, it restores the vein's lumen back to its original size. Doctors have found that this reduces brain pressure in some people.

### **Does VSS work?**

At present there are no large controlled studies that have answered this question. Current research is limited in this area. However, from the studies published patients do commonly report an improvement in their symptoms. It is important to bear in mind that it is impossible to predict the response that one person can get before they have the surgery. As with any intervention there are risks and complications to consider, see below.

### **Are all stents the same?**

Stents will vary in length and diameter to accommodate for the narrowing in the vein but all function to keep the vein from narrowing. Some stents expand by themselves while others use balloons to open them up to relieve the narrowing.

### **What do I need to do before the surgery?**

Before the surgery, you may be given blood thinning tablets for a week before the surgery. Your doctor may require you to have further head imaging tests. This can be done with either magnetic resonance venography (MRV) or computerised tomography venography (CTV).

If the CTV or MRV shows a narrowing of the venous sinus, retrograde venography is performed to definitively confirm the narrowing. This is a procedure performed under local anaesthetic, but you may have the option of sedation to help you relax. A small tube (catheter) is placed into the femoral vein (a groin vein, at the inside top of your leg). This tube passes through the blood vessels to eventually reach the venous sinus in the head. From here, we are able to use X-rays and a special dye to confirm the narrowing. Further measurements of the pressure (“pressure gradient”) either side of the narrowing are taken to further confirm that the narrowing. You may experience a headache during this test.

### **Will I have an anaesthetic for the surgery?**

Stent insertion is done under general anaesthetic to prevent any pain during the operation.

### **How is the stent put in?**

The surgery is done in an operating theatre, under general anaesthetic, with a dedicated team of nurses and doctors including a radiologist and an anaesthetist. The team will each introduce themselves to you and answer any questions or concerns you may have.

Once you are happy to begin the procedure, the anaesthetist will insert a thin tube into a vein in your arm via a needle to administer the drugs needed to put you to sleep for the duration of the operation.

The radiologist will then pass a catheter into your femoral vein that will eventually reach the sinus vein in the brain. A second smaller tube is inserted in the first catheter and the stent is pushed through this and into the vein. At this point, both tubes are removed to leave the stent which will either be self-inflating or be ballooninflated. This keeps the vein open and improve blood flow.

As the procedure is done under general anaesthetic, you will be transferred to a recovery ward for close monitoring to ensure you recover well from the anaesthesia. Some cases require further monitoring in a high dependency unit.

What are the risks to the whole procedure including pre-operative assessment?

The pre-operative investigation and the surgery has risks that will be discussed with you by your doctors before you decide to have the surgery.

General anaesthetics have some common side effects. Your anaesthetist should discuss these with you before your surgery. For further information visit: <https://www.nhs.uk/conditions/general-anaesthesia/>

After the surgery there can be a large bruise in the groin area (inside top of the leg), this is uncommon and rarely a significant problem as it will disappear over time.

Using X-rays (when having the CT) carries a small risk of hair loss. However, this is temporary and uncommon. Remember X-rays are harmful to an unborn child and it is important to tell your doctor if you may be pregnant.

The use of contrast dye could cause a rare allergy and rarely results in damage to your kidneys. Your doctor will have requested blood tests to look at your kidney function and make sure you are not at any undue risk of kidney damage.

You will be recommended to take blood thinning medication before the operation and after the operation for several months (to keep the stent from becoming blocked with a blood clot). Blood thinning tablets cause a risk of bleeding. This can be bleeding from the nose, gums or stomach and lining of the gut. Please notify your doctor if you have had previous bleeding problems or a family history of bleeding or clotting tendencies.

In less than 5% of people that have this type of procedure a stroke can happen either due to a clot or due to bleeding from a blood vessel. Strokes can be minor with no life-long complications or can be debilitating with life-long effects on speech, vision or movement. They can also rarely cause death.

### **How long do I need to stay in hospital when I have the stent put in?**

People will generally be monitored for three or four days and be discharged afterwards if recovery is going as expected. Some people may require a longer hospital stay.

### **How will I feel as I recover?**

After the procedure it is normal to experience headaches which resolve within the first few days but can last up to weeks. Your doctor will prescribe medication to help with this. If your headache becomes **severe** or you become **drowsy, feel sick** or experience **severe neck stiffness** you should immediately go to the nearest accident and emergency department.

### **Do I need to take time off work after having the stent put in?**

You should plan some time off work until you are back to how you felt prior to the operation. Discuss this with your doctor as to how many days off you might need.

### **Does the stent last forever?**

In most cases, the stent will remain in the brain for the rest of your life. In some cases, if the stent gets blocked you may need a further operation.

### **Can I drive after having a stent procedure?**

There are currently no restrictions on your ability to drive after recovery and discharge from hospital.

### **Can I fly after having a stent procedure?**

Yes, and the stent will not set off any metal detectors at the airport.

### **Can I have sex after my stent procedure?**

Following a full recovery, you can return to your previous activities and this includes sex.

### **Can I get pregnant after my stent procedure?**

The stent does not affect your ability to become pregnant and poses no additional risks.

### **Should I avoid any sports if I have a stent?**

We recommend against sports where there is a high chance of repetitive blows to the head such as boxing or mixed martial arts. However, other sports are safe to practice.

## Where can I get more information?

Further information about IIH can be found at the IIH UK website below. Please feel free to ask your doctor any questions you have regarding this procedure. [www.iih.org.uk](http://www.iih.org.uk)

## Write notes or questions for your appointment here:

A team of people contributed to this booklet. It was written by Y Abdallah. Reviewed by S Mollan. It was assessed in the draft stage by the ophthalmology nursing team at University Hospitals Birmingham (UHB). It was reviewed by a group of patients who have IIH, and also assessed by friends and family that attended the Joint Idiopathic Intracranial Hypertension clinic at UHB. It was critically reviewed by the IIHUK trustees. S Mollan is responsible for the final version. The views expressed in this booklet are of the authors and not their employers or other organisations.

Please note we have made every effort to ensure the content of this is correct at time of publication, but remember that information about the condition and drugs may change. This information booklet is for general education only.

Version 4.0 (Reviewed August 2021) Review by July 2023