

## Stent placement for severe IIH - Patient information



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### Problem

- IIH is usually due to a localised narrowing in a vein at the base of your brain. This causes a problem in the pressure system inside your head, by interfering with the drainage of CSF (the fluid around your brain, spinal cord and the vision nerves behind your eyes).
- A tube called a stent can be placed inside the vein at the point of narrowing, to open it up and normalise the pressure system.
- You will be considered for this procedure if tablets alone are not keeping your IIH under control.

### Testing

The first step is a test to be sure that there *is* a narrowing in the vein causing pressure to build up. This will be done by a radiologist in a Hospital Imaging Department, usually Royal Prince Alfred in Sydney.

- A fine tube is introduced through a vein in the groin, and threaded up to the area of the narrowing.
- The pressure is then measured above and below the narrowing. If the pressure is very high above but much lower below, this proves that the narrowing is the problem.
- The test is performed while you are awake, with a little light sedation if need be, as a general anaesthetic affects the pressure measurements.
- Once it has been determined that there is a narrowing as the cause of the pressure issue, the radiologist will discuss with you the benefits and risks of the actual procedure (insertion of the stent). The procedure is not performed on the same day.
- If a driver is available, the trip to Sydney and back can be made on the same day as testing. However it may be more convenient to stay in Sydney the night before or the night after, to make the process less tiring. If you are travelling alone, it is best to stay overnight.

### Preparation for testing

1. You will usually need a blood test, which will be arranged by me. Once I have the results, I will write a referral to the radiologist, who will then call you to arrange a date for the test.
2. Your pressure medication of Diamox and/or Topamax will be **reduced or ceased 2 weeks prior to the test**, and then resumed immediately afterwards.
3. Please take to your test a USB with images from all previous brain scans. You can arrange this by calling the Imaging service who performed the test eg. Canberra Hospital Imaging can be contacted on 02 5124 2159.

### Procedure

This is again done via a vein in the groin, by the same radiologist who did the testing.

1. **You will need to take blood thinners for 1 week before the procedure**, and the radiologist will give you a script for these - usually Aspirin 100mg and clopidogrel 75mg.
2. Your pressure medication of Diamox and/or Topamax is taken as normal up to the day before stent placement, and then rapidly reduced afterwards.

3. Placement of the stent requires a general anaesthetic. In preparation for this, you will need to come to the Hospital the day before to attend the Anaesthetic Pre-admission Clinic.
4. You will be admitted to hospital on the day of the procedure, and will stay in hospital the night of the procedure for observation. Most people go home the next day.
5. As there is often some headache after placement of the stent due to stretching of the vein, it is recommended that you plan to have two weeks off work. You may need less, but it's best to plan for a fortnight and go back early if you feel OK.

### Efficacy and safety

1. My research shows that 96% of patients who have this procedure get rid of all swelling of the vision nerves, and 81% can stop taking medication [Stenting Reverses Medically Refractory IHH](#).
2. Those who have headaches usually notice a big reduction in headache too.
3. Stenting has a very acceptable safety profile, but the radiologist will discuss the risks with you in detail, to help you decide if you wish to go ahead with the procedure.
4. The main risk is developing a clot inside the stent, and this is prevented by taking **blood thinners for a week prior to the procedure, and for 12 months afterwards**. This means that any upcoming surgery or dental work should be undertaken prior to the procedure.

### Hospital and cost

I recommend the doctors at Royal Prince Alfred Hospital who pioneered this technique in Australia, as they continue to do the highest numbers of these procedures nationally.

- The test and the procedure are fully covered by Medicare.
- Private fees apply to your follow-up appointments with me.

### Follow up after the procedure

- **It is extremely important that you take your blood thinners as directed for 12 months after the procedure. Failure to do so exposes you to a life-threatening risk of a clot inside the stent.**
  - First 3 months – both tablets – usually Aspirin 100mg and clopidogrel 75mg
  - Next 9 months – Aspirin 100mg alone
  - If you tolerate Aspirin well, ongoing use after the first 12 months on Mon and Thu each week is recommended, unless there is a reason to stop it
- After stent placement, swelling of the vision nerves usually settles rapidly. You will be seen by me a few weeks after the procedure to check on this.
- Your Diamox will be halved immediately after the procedure, and then decreased further at your check-up if all is going well. Any Topamax will be reduced by 25mg each week.
- Once you are stable you will be discharged from my rooms to a six-month follow-up with your optometrist. You will then require lifelong annual checks with the optometrist.

### What to watch out for after the procedure

- Although this is extremely rare, sudden onset of severe persistent headache after a stent could indicate a clot inside the stent. You should seek assessment from your optometrist, GP or me.