

LOW FLOW LYMPHATIC MALFORMATIONS (LFVM)

DIRECT STICK SCLEROTHERAPY

PATIENT INFORMATION

This leaflet tells you about the treatment for **lymphatic malformations**. It explains the options, what is involved and what the possible risks are. It is not meant to replace informed discussion between you and your doctor, but can act as a starting point for such discussions. If you have any questions about the procedure please ask the doctor who has referred you or the department which is going to perform it.

WHAT IS LYMPHATIC MALFORMATION?

Lymphatic malformations are congenital (you are born with them) and are a collection of cysts filled with clear fluid called lymph. The cysts have a thin wall and no purpose. They can be very small (microcystic) or large (macrocytic). They can suddenly swell and bruise causing pain, can become infected and leak fluid.

WHAT ARE THE TREATMENT OPTIONS AVAILABLE?

There are 3 options:

- 1. Observation & conservative management** : An explanation of the natural history with advice on the treatment of thrombophlebitis, compression garments and contacts.
- 2. Surgery** : This can be an option for focal lesions or debulking especially in the very young. There is a tendency for the malformation to return.
- 3. Direct Stick Sclerotherapy (DSS)** : Image guided injection of a chemical into the malformation is now universally accepted as the treatment of choice.

WHAT IS DIRECT STICK SCLEROTHERAPY?

Direct stick sclerotherapy is a procedure used to treat lymphatic malformations. Sclerotherapy involves injection of a liquid medicine (sclerosant) that irritates the cysts causing them to scar and shrink. Often a course of treatment is required to obtain the desired reduction of swelling, pain and infections. There are a number of different sclerosant used that depend on whether the lymphatic malformation is microcystic or macrocystic. .

WHY DO YOU NEED SCLEROTHERAPY?

Lymphatic malformations can cause problems with daily activities. They cause swelling, which can be complicated by bleeding and infection.

This causes the area to become very painful. If the skin is involved with the microcystic (small cysts) malformation they tend to leak small amounts of lymph. Other imaging tests (MRI & Ultrasound) will have been performed before to aid the diagnosis and help in deciding the best form of treatment in your case.

WHO HAS MADE THE DECISION?

The multidisciplinary team responsible for your care will have decided after reviewing the imaging and meeting to discuss with you.

WHAT HAPPENS BEFORE SCLEROTHERAPY?

You will have a pre-admission assessment, which may involve taking blood samples, photographs and other tests. The procedure will most likely be carried out under local anaesthesia /sedation as an adult and a general anaesthetic as a child. The procedure is generally carried out as a day case.

You may be asked not to eat for four hours before the procedure, although you may still drink clear fluids such as water.

If you have any allergies, you must tell the radiology staff before you have the test.

WHO WILL YOU SEE?

On admission day Dr McCafferty will see you on the ward and explain the procedure in more detail and discuss any questions you may have before asking you to sign a consent form.

WHAT HAPPENS DURING THE SCLEROTHERAPY?

You will be asked to wear a hospital gown and a small cannula (thin tube) will be placed into a vein in your arm.

You will be asked to lie flat on your back on the special X-ray table and monitoring devices will be attached to your chest and finger. You will receive oxygen via a mask.

Sclerotherapy is performed under sterile conditions and the interventional radiologist and radiology nurse will wear sterile gowns and gloves to carry out the procedure. The skin overlying the swelling will be swabbed with antiseptic and you may have a small injection of a sedative to make you feel sleepy. Using ultrasound guidance, several small needles will be placed in the swelling. A small amount of dye (contrast agent) is sometimes injected to confirm the needle is correctly positioned and to calculate the correct volume of sclerosant. The liquid sclerosant is injected as foam and the procedure is finished. Sometimes it is not possible to place a needle in a safe position and the procedure has to be abandoned.

WILL IT HURT?

There will be pain and swelling following the procedure due to inflammation. This is the desired effect and may last 10-14 days. If the malformation does not swell, it is more likely that the treatment will not work. Painkillers and anti-inflammatory medication can help during this period e.g. Paracetamol & Ibuprofen.

ARE THERE ANY RISKS?

Sclerotherapy is a safe; but as with any medical

procedure there are some risks.

There will be pain and swelling following the procedure. If the malformation does not swell, it is more likely that the treatment will not work. The pain should subside over a day or so and the swelling over about 5–10 days. This usually responds to Paracetamol or Ibuprofen.

If the malformation is close to, or just under the skin, there is a small risk of skin blistering and rarely skin loss. If this were to occur, it usually requires simple bandaging but rarely may require an operation.

Very rarely, nerve damage can occur if the malformation is close to a major nerve. This is usually a temporary situation due to the nerve being 'bruised'. However, although extremely rare, this can be a permanent loss. This will be taken into account by the multidisciplinary team of doctors before deciding whether this type of treatment is suitable for you.

There is a chance the malformation may not shrink or may even grow again later, in which case further treatment may be required. This will be decided when you visit the clinic for a follow-up appointment in the months following treatment.

If a general anaesthetic is required, this carries an extremely small risk.

Each sclerosant agent has slightly different side effects. If Bleomycin is considered as a treatment, please see Bleomycin information leaflet.

HOW LONG WILL IT TAKE?

Every patient is different, and it is not always easy to predict; however, expect to be in the radiology department for about an hour.

WHAT HAPPENS AFTERWARDS?

You will be taken back to your ward. Nursing staff will carry out routine observations including pulse and blood pressure and will also check the treatment site. You will generally go home later that day. You will only stay overnight if the pain and swelling is not adequately controlled. Please see "What to expect after sclerotherapy" leaflet for further information.

FINALLY

Some of your questions should have been answered by this leaflet, but remember that this is only a starting point for discussion about your treatment with the doctors looking after you. Make sure you are satisfied that you have received enough information about the procedure.

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