Lymphatic malformations and their treatment

Information for patients
Hi I’m Nurse V. Well, I have been asked to talk to you about your lump.
How do you say Lymphatic Malformation?
If you try Limp-fat-ic Mal-for-may-tion it should be a little easier to say or we could just call it a lump for now if you like?

So what is your lump and why is it there?
Do you know what lymph glands are? I’m sure you do, but just in case you are not sure, lymph glands help carry fluid around your body and are normally very useful. However sometimes they can get all tangled up and become not useful at all. In fact between me and you they are a bit naughty!

These naughty glands don’t help blood go round your body but cause your lump.

That sounds bad
Don’t worry, I know your lump can become bigger and hurt from time to time but it isn’t dangerous.

In fact I think your lump may have been with you all your life and may have been very small when you were born.

So what can we do about your lump?
We need to do a few things to make sure you get the right treatment. Firstly we will need to take some special pictures of your lump to see what it looks like. Once we have these pictures we will invite you and your parents or carers to come and see us in a clinic. Do you know what a clinic is? I’m sure you do but just in case you don’t a clinic is where you meet a doctor who will chat to you and your parents or carers about your lump and how we could treat it.
The doctor may ask you questions about your lump and how it makes you feel.

We may also then take your special pictures to a big meeting of doctors and nurses who will talk about your lump and the best way to treat it.

Once all these people have had a good think we may suggest a few ideas to help you.

I have put the ideas below so you can have a think about them too.

**Do nothing:**
If your lump is not annoying you and not hurting or swelling, and you can play with your friends and do your hobbies without any problems, then we may leave the lump alone. This does not mean you cannot see us again if your lump starts being a bit naughty.

**Tight socks:**
If your lump is annoying you we may think that wearing tight socks up to you knee or even up to you thigh will help. We can also make tight sleeves if the lump is on your arm.

We write to a special department called the Orthotics (tricky word alert, if you cannot say it try this, Or-tho-tics) Department (they are very nice people) so they can measure you to make sure the sock or sleeve fits well.

Don’t worry this is just like being measured for a new pair of shoes but instead of your feet they will measure where your lump is.

We then invite you and your parents or carers back to clinic
(do you remember what a clinic is?) to see if the tight socks or sleeve has stopped your lump from being annoying.

**A little operation:**
If your lump is really annoying and you and your mummy, daddy or carers agree that a small operation would help we will place you on our waiting list (a waiting list is just like a queue for treatment).

**What happens when you have your small operation?**
On the day of your operation, you will come into a special ward for children only. You will meet a lot of new people who will make your stay as happy as possible. They may chat with your mummy, daddy or carers about your operation.

Your operation will be done in Radiology Theatres. This is a special theatre which does lots of operations including small operations like the one you are having. Remember you can bring your favourite teddy or toy with you to cuddle but you may be too busy laughing at mummy, daddy or your carers as they get dressed in special clothes so they can come with you into the room where your small operation will be done.

When you are in the room you will be given a special medicine that makes you have a bit of a sleep and then, hey presto when you wake up again your operation is done. You see there is nothing to worry about at all.
After your operation

Your lump may be swollen and sore after your operation for a week or a bit longer. I know this will be annoying but it means the treatment is working.

One of the medicines we may give you called OK432 may make you feel like you have a cold and shivery for a few days, don’t worry this is normal.

If we give you a medicine called Doxycycline… (Tricky word alert! to say it imagine a few dogs on a bikes and say “dogs is cycling” and boom you’ve got it)…. we may ask you to be careful of the sun for a while. We will tell your mummy, daddy or carers about this so don’t worry.

Your parents or carers can give you medicine for the pain and shivery cold if you get it.

Your nurse specialist (a nurse who looks after people with lumps like yours) will call your mummy, daddy or carer a week and eight weeks after your operation to make sure you are ok.

I hope this has helped you understand everything about your lump but if not please do ask and remember don’t worry.
See you soon

Nurse V. Well