

Bleomycin

Information for teenagers



Hello, I'm Jon - your Nurse Specialist

I am a radiology nurse and I also specialise in vascular malformations much like the one you have.

I work alongside X-ray doctors or radiologists who also specialise in vascular malformations.

Radiologists are specialists in reading and making sense of X-rays, CT's and MRI's, for example. They use their expertise to help other doctors figure out what's going on inside patients.

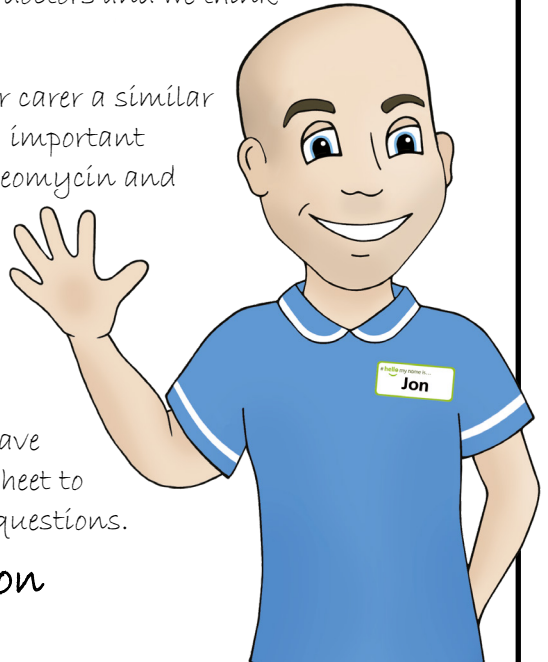
Radiologists often carry out treatments as well.

Your family doctor has asked us to see you as you have a malformation that has been bothering you. We have talked about your malformation with other doctors and we think bleomycin will help.

We have given your parents or carer a similar leaflet, but we think it is very important that you understand about bleomycin and the treatment we are offering and so we have written this leaflet especially for you which explains everything. We hope you find it useful.

If you have any questions I have left an area at the end of the sheet to write down your thoughts or questions.

Have a great day! **CNSJon**



What is bleomycin?

Bleomycin is a medicine that has been used for a long time in the treatment of other illnesses.

Your doctor thinks bleomycin is the best medicine to treat your malformation.

Why is it the best medicine?

- To help your particular type of malformation.
- Your malformation is in an area where we would be keen to avoid swelling as a result of treatment, such as near the eye.
- If previous injections into your malformation have failed.
- If your malformation is close to your skin.

Is it safe?

In a very few cases, when it has been used in much higher doses and has been injected straight into the veins, bleomycin can cause damage and changes to the lungs and how they work.

This can happen during the treatment or afterwards.

Doctors think this is extremely unlikely to happen when bleomycin is being used to treat malformations such as yours, as the doses are much lower and the medicine is not given in the same way.

However, we will check your lungs before the procedure, usually using a chest X-ray and some very simple, painless breathing tests. This gives us a picture of your healthy lungs and if we need to test your lungs again later, we will have this picture to help us.

Extra oxygen may cause lung problems during and after your treatment with bleomycin. This can occur months or years after treatment.

We have asked your parents or carers to:

1. Inform your doctors or dentists that you have been treated with bleomycin before you receive any type of surgery.
2. Make sure you carry a card (we will provide these) or wear a wrist bracelet (e.g., MEDICALERT®) to alert health care providers.

We suggest avoiding activities or occupations which use increased oxygen pressure, such as scuba diving, for the rest of your life.

You must also inform any of the above if your parents or carer forget and make sure you carry your card or wear a bracelet! I'm sure you will!

Always tell your parents or carers if after treatment with bleomycin you feel:

- Wheezy
- You get a cough
- You feel unwell
- You find breathing harder

You should also let us know if any existing breathing problems get worse. If necessary, we can arrange for you to have tests to check your lungs.

Very rarely, bleomycin can cause some change of colour of the skin or nails or make some hair fall out. This usually gets better with time.

Your skin is more likely to go a funny colour because of the sticky pads from a heart monitor for example or any sticky plasters that are stuck on you. It can also happen if you scratch your skin after treatment. Therefore we will be very careful to put sticky plasters or monitoring pads onto parts of the skin that are not noticeable and we may also give you some medicine that helps you not to scratch (antihistamine).

Assessments carried out before bleomycin sclerotherapy

You will meet a radiologist in clinic who will explain the treatment in more detail with your parents or carer and discuss any questions they may have.

If you have any questions don't be shy - remember it's your malformation and your questions are important!

Your parents or carer will be asked to sign a consent form giving permission for you to have sclerotherapy.

It is important that you know you do not have to make a decision straight away; the reason we see you in clinic and give you patient information sheets such as these is so you and your parents or carers can make a well-thought-out decision regarding your treatment.

If you would like more time to think then please let the doctors know. There is a section at the end of this information sheet for any thoughts or questions you may have after you meet with the Radiologist.

You will also need to be checked to make sure you are well enough for the procedure and to confirm that your lungs are healthy. If you have any medical problems, please tell the nurses and doctors. You may well see an anaesthetist at the same time who will talk to you about your anaesthetic.

Follow-up carried out after bleomycin sclerotherapy

We will send a letter to your family doctor so they are aware of the procedure you have had.

We will also provide you with a special card advising any medical professional that you have had bleomycin.

We will contact your parents or carer at one, four and eight weeks by phone when we will check how you are.

We will also review you at an outpatient appointment at three months.

Always remember, I'm happy to talk with you.

Jon

**Jonathan Pearce,
Nurse Specialist Radiology Theatres**



Do you have any thoughts or questions?

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Your views matter



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