

Bevacizumab (Avastin®)

for the treatment of neurofibromatosis type 2

This leaflet aims to answer your questions about having bevacizumab to treat your neurofibromatosis type 2. If you have any questions or concerns, please speak to a doctor or nurse caring for you.

What is bevacizumab?

Schwannomas are non-cancerous tumours of the tissue that covers nerves. Bevacizumab is a drug that targets specific proteins in the body. Bevacizumab targets a protein (known as VEGF) that helps make new blood vessels (arteries, veins etc). It is thought that bevacizumab works by restricting the blood supply to your schwannomas, which may make them shrink or stop growing.

Why am I being offered bevacizumab?

Bevacizumab is used to try to shrink your schwannomas, or to stop them from growing any further.

Some people may be worried by information about bevacizumab that they have seen, for example on the internet, because it is also used to treat cancer. We are using this drug to treat your schwannomas, which are non-cancerous (benign) tumours.

Taking an unlicensed medicine

Bevacizumab is not licensed for the treatment of neurofibromatosis type 2, as it is a very rare condition and the large clinical trials needed to obtain a license for this condition are not possible. However, your clinical need cannot be met by medicines that are currently licensed, and small studies have shown that bevacizumab may shrink the tumour size in some patients with neurofibromatosis type 2. Although there is no guarantee of a successful outcome, we are hopeful that you will obtain some benefit from this treatment. You are being offered this treatment because your current condition meets the very strict national guidelines that are in place for giving this drug.

The leaflet **Unlicensed medicines – a guide for patients** has more information about unlicensed medicines. If you would like a copy, please ask your doctor, nurse or pharmacist. Alternatively, you can call the pharmacy medicines helpline – contact details are at the end of this leaflet.

Do I need to have any tests before I start treatment?

Before you start treatment with bevacizumab you will need to have a number of investigations including an MRI scan and blood and urine tests. MRI stands for magnetic resonance imaging – this is a detailed scan of the inside of your body. It uses a strong magnet and radiowaves to take lots of detailed pictures, which will give us more information about changes in your condition than an X-ray could. It also does not involve the use of radiation.

We will tell you more about these procedures before you have them, and will give you a chance to ask questions.

What should I do if I am planning a pregnancy or breastfeeding?

Bevacizumab can harm your unborn baby if taken during pregnancy. Women of childbearing age must use effective contraception during treatment with bevacizumab, and up to six months afterwards. Discuss with your doctor before you start treatment if you are planning on becoming pregnant in the future. It is not safe to breastfeed if you are taking bevacizumab.

If appropriate, we will offer you a referral for sperm banking and embryo storage

How do I take the medicine?

We will give you your bevacizumab in hospital every two, three or four weeks. On the day of the appointment we will take your blood pressure and also do a blood and a urine test, to make sure you can have the next dose.

The doctor will work out the dose to prescribe you, based on your body weight. Bevacizumab is given as a fluid through a needle inserted into a vein in your arm (intravenous infusion). At your first appointment, it will take 90 minutes for the dose to be given. As long as you don't experience any problems during or shortly after the first dose, the doses at appointments after this can be given more quickly (reducing down to 30 minutes).

You will be able to go home after your treatment, as soon as you and the nurses are happy that you can leave. You do not have to stay in hospital overnight either before or after your treatment.

How soon will the bevacizumab work?

Bevacizumab can work very quickly, and treatment has three possible outcomes:

- shrinkage of the schwannomas (although you may not notice the effects of the schwannomas shrinking)
- prevention of further growth of the schwannomas
- no impact on your schwannomas.

We will know if the drug is working because you will have an MRI scan before you start the treatment, and then at three months and six months after you have started the treatment. By looking at the scans we will be able to see if your tumours have shrunk or stayed the same size.

How long will the treatment go on?

Treatment is split into three phases, depending on the effect it has on the growth of your tumours:

- **Phase 1** – Initial treatment for three months to see if bevacizumab has any effect. If your tumours have continued to grow during the first three months of treatment, we will stop giving it to you as it is not working as we would hope.
- **Phase 2** – If bevacizumab has had an effect, for example the tumour is stable or smaller, we will continue treatment for another three months to confirm the benefits.

- **Phase 3** – If the tumours shrink or stay the same size, and this continues at your six-month review, you can remain on treatment with regular monitoring.

Long-term treatment will only be considered if the bevacizumab is shrinking or preventing further growth of your schwannomas.

What should I do if I am unable to have one of my treatments?

If you are unable to come to hospital for one of your bevacizumab doses because you feel unwell (for example if you have the flu), you will probably be able to continue with the drug when you are better. Your doctor will need to see you as usual to ensure that they are happy that you can carry on with your treatment.

If you are undergoing any surgery, you will need to stop bevacizumab treatment for four weeks before and four weeks after this surgery. You will then need to see your doctor to see if your treatment can continue.

Are there any side effects?

Each person's reaction to this drug therapy is different. Some people have very few side effects, while others may experience more problems. The side effects described here will not affect everyone who is given bevacizumab.

By taking your blood pressure and checking your blood and urine each time you are about to have the drug, we will make sure that you are well enough to have the treatment and therefore reducing the risks of some of the side effects.

Below we have outlined the most common side effects, but have not included those that are very rare and therefore extremely unlikely to affect you. If you notice any effects that you think may be due to the drug, but which are not listed below, please discuss them with your doctor or nurse.

Blood clots

If you are immobile we will recommend that you wear anti-embolism stockings (compression stockings) to help stop blood clots from happening while you are being treated with bevacizumab. If you develop a painful, swollen limb or experience chest pain or shortness of breath, you must go immediately to your local emergency department (A&E) to seek medical help.

High blood pressure and circulatory problems

You may be at increased risk of developing circulatory problems such as a stroke or angina (chest pain) while taking bevacizumab. We will check your blood pressure regularly during your treatment. If you have headaches, nosebleeds or feelings of dizziness let your doctor know.

Allergic reactions

It is common to have a slight allergic reaction to bevacizumab, but some people have a more severe reaction. Signs of a reaction include skin rashes and itching, a feeling of swelling in the tongue or throat, irritation of the nasal passages, wheezing, a cough, and breathlessness. We will monitor you closely during your treatment, but it is very important to tell your nurse or doctor if you have any of these symptoms.

Tiredness and a general feeling of weakness

It is important to allow yourself plenty of time to rest, particularly after your first dose of bevacizumab. Do not arrange to do too much on the day or two after your first dose, in case you are severely affected.

Feeling sick (nausea) and being sick (vomiting)

If this happens, it may begin a few hours after the treatment is given and last for up to a few days. Your doctor can prescribe very effective anti-sickness drugs to prevent or greatly reduce your nausea and vomiting. If the sickness is not controlled tell your doctor. They can prescribe other anti-sickness drugs which may be more effective.

Bruising or bleeding

Bevacizumab can reduce the production of platelets (which help the blood to clot). Let your doctor know if you have any unexplained bruising or bleeding.

Lowered resistance to infection

Bevacizumab can reduce the production of white blood cells by the bone marrow, making you more prone to infection. Contact your doctor or the hospital straight away if:

- you feel like you are getting a temperature or fever
- you suddenly feel unwell (even with a normal temperature).

You will have a blood test during your treatment to make sure that your blood cells have recovered. Occasionally it may be necessary to delay your treatment if your blood count is still low.

Slow wound healing

Wounds may take longer to heal while you are having treatment with bevacizumab.

Diarrhoea

This can usually be easily controlled with medicine, but let your doctor know if it is severe or if it continues. It is important to drink plenty of fluids if you have diarrhoea. You can ask the doctor to prescribe you an anti-diarrhoeal medicine to take home if you are finding this side effect troublesome

Constipation

Let your doctor know if you develop constipation. This can often be relieved with a high-fibre diet or laxatives.

Less common side effects

Sore mouth and taste change

Your mouth may become sore, or you may notice small ulcers during this treatment. Drinking plenty of fluids and cleaning your teeth regularly and gently with a soft toothbrush can help reduce the risk of this happening. Tell your nurse or doctor if you have any of these problems as they can give you special mouthwashes and medicine to prevent or clear any mouth infection.

Headaches

Let your doctor know if you start to develop headaches while you are having bevacizumab treatment.

Loss of appetite

You may find that you do not feel like eating. A dietitian or specialist nurse at the hospital can give advice on boosting your appetite and eating well.

Effects to the kidneys

Bevacizumab can sometimes temporarily change the way that your kidneys work. You will have blood tests to check that your kidneys are working well.

Changes in the way your heart works

Symptoms of this will include chest pain, difficulty breathing and swelling of the ankles (because of water retention). Let your doctor know if you develop any of these symptoms.

Pain in the area of the tumour

Some people may have pain in the area of the tumour.

If you have any questions about these or any other side effects, talk to your doctor or nurse. It is important to let them know if you have any symptoms or side effects that you think may be related to any treatment you are having.

Useful sources of information

Nerve Tumours UK

Provides information, support and advice about neurofibromatosis.

t: 020 8439 1234 **t:** 07939 046030 (helpline – Monday and Wednesday only 9-5pm)

w: www.nervetumours.org.uk

Contact us

If you have any questions or concerns, please contact the nursing team at the **Neurofibromatosis Department** (Guy's Hospital)

t: 020 7188 9976 (Monday to Friday, 9am to 5pm).

Out of hours, please contact the hospital switchboard on 020 7188 7188 and ask for the bleep desk. Ask the bleep operator to bleep the **neurology consultant on call** and wait for a response. This will connect you directly to the on call neurology consultant.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748, Monday to Friday, 9am-5pm

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch.

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111 **w:** 111.nhs.uk

NHS website

Online information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.

t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership

Was this leaflet useful?

We want to make sure the information you receive is helpful to you. If you have any comments about this leaflet, we would be happy to hear from you, fill in our simple online form, **w:** www.guysandstthomas.nhs.uk/leaflets, or **e:** patientinformationteam@gstt.nhs.uk

Leaflet number: 3481/VER3

Date published: March 2019

Review date: March 2022

© 2019 Guy's and St Thomas' NHS Foundation Trust

A list of sources is available on request