

Bevacizumab (Avastin®) treatment for Neurofibromatosis Type 2 (NF2)

Information for patients



This booklet has been written to give you more information about bevacizumab (commonly known as Avastin). This is a drug that can be given to people with Neurofibromatosis Type 2 (NF2) to try and stop, shrink, or slow the growth of schwannomas (benign nerve tumours).

What is Avastin?

Avastin is a type of drug known as a monoclonal antibody.

Monoclonal antibodies are able to recognise and then stick to specific proteins on the surface of tumour cells. They are sometimes called a 'targeted therapy' because they are designed to target specific cells.

Monoclonal antibodies work by triggering the body's immune system to attack the tumour cells, causing the cells to destroy themselves. They also block specific proteins from being activated, that would normally help the tumour cell to grow. This may stop the cells from growing and dividing, and may also prevent the tumour cell from developing a new blood supply.

How does Avastin work?

Avastin stops the tumour from developing new blood vessels. This reduces the supply of oxygen and nutrients, which can cause the tumour to shrink, stop growing or grow more slowly. This kind of drug is called an angiogenesis inhibitor.

Why have I been prescribed Avastin?

Avastin is given to people with NF2 when a schwannoma has grown by a specific amount or more over the previous year. The schwannoma will be measured by looking at and comparing MRI scans over the course of a year.

Evidence suggests that Avastin is more effective in faster growing tumours. National guidelines state that patients need to have schwannomas that meet the specific growth rate criteria for them to be considered for treatment with Avastin.

If the NF2 Centre in Oxford decides you meet the criteria for Avastin treatment, then your case will be reviewed by other NF2 Centres. This is because we are not authorised to give this treatment until it is approved by a second national centre.

Avastin is given for the treatment of NF2 initially for six months, with three monthly MRI scans and clinic reviews. If a tumour starts to grow despite having Avastin treatment, then the drug will be stopped. The drug will also be stopped if you suffer significant side effects. These are discussed later in this booklet.

Avastin cannot be given one month before or after any surgical procedure or operation, because it can affect how well you will heal.

What does Avastin look like?

Avastin comes as a colourless fluid. It is given through a drip into a vein (intravenous infusion), usually in the arm. It is normally given once every two to three weeks. The infusion is given over 90 minutes. If you tolerate the drug well this time can be reduced to 60 and then 30 minutes.

You will be asked to remain at the hospital for some time after each of the first few doses of Avastin, to make sure you have no reaction from the infusion. When you have received several doses of Avastin you will be able to go home after a shorter amount of time.

What will happen before I can have Avastin?

Before Avastin can be given, you will need to meet certain screening criteria. This includes blood tests, a urine test, measuring your blood pressure, measuring your height and asking you some questions about your quality of life. MRI scans of your head and hearing tests will also be done, to give us a baseline so that we can measure the effect of the drug following treatment.

We will ask you to sign a consent form to confirm you are happy to go ahead with the treatment.

Before each treatment we will take blood and urine tests, your blood pressure and your weight.

Will Avastin affect my fertility?

Although we have no evidence that Avastin affects future fertility, if you are male you will be offered sperm preservation (sperm banking) and if you are female you will be offered egg/embryo preservation if you wish to, prior to starting Avastin.

On-going monitoring as part of your Avastin treatment

As a condition of being on Avastin, you will need to have regular reviews to monitor your response to the treatment. This is a requirement from the Highly Specialised Services commissioning team that funds your treatment and applies to all patients receiving Avastin at the four National NF2 Centres across the UK.

You will be asked to come for an MRI scan and Avastin clinic appointment before you begin your treatment. You will also need to come for an MRI scan and to the Avastin clinic at three monthly intervals in Year 1 and at six monthly intervals in Year 2. The Avastin clinic appointment will include:

- a neurology assessment
- a quality of life questionnaire
- an audiology assessment (hearing test), if this applies
- a timed 10 metre walk, if this applies.

After 24 months you will have a discussion with the NF2 Team about your response to the treatment and whether this is still the most appropriate management for your tumour(s).

If the team recommend that you continue to receive Avastin treatment after Year 2, you will carry on having MRI scans and coming to the Avastin clinic every 6 months, for as long as you are being treated.

Should you stop receiving Avastin, you will still be required to come to regular Avastin clinic appointments and for MRI scans up to 3 years after the last dose. This is to monitor the possible long-term side effects of Avastin.

What are the side effects of Avastin?

As with any drugs, Avastin can cause side effects. Each person reacts very differently to drugs and some people will have very few side effects while others may experience more. The side effects described here will not affect everyone who is on Avastin. The side effects can be put into two categories:

1. Side effects that relate to the infusion (side effects that occur during or up to or 24 hours after you have received the drug).
2. Side effects that may occur for days or weeks after receiving the drug.

Very few people have infusion-related reactions. If they do occur, they are often mild and rarely severe. If a reaction does happen it is most commonly during or shortly after the first or second infusion. This is why you need to remain in hospital for a longer period after receiving the first few infusions. If you have a reaction during the infusion, it can be stopped and any side effects you experience can be treated.

During your treatment you will be monitored closely, but it is important to let the nurse or doctor know if you do not feel well or have any of the following symptoms:

- flu-like symptoms, such as fever, chills or aching all over
- red, warm and itchy lumps on your skin (like nettle rash)
- feeling that your lips are swelling or that your tongue or throat is swollen
- feeling breathless, wheezing, developing a cough or suddenly having difficulty breathing
- pain in your tummy or your back
- any tightness in your chest or pain across your chest.

It is rare for these infusion related reactions to happen several hours after your treatment, but if you do develop any of these symptoms or feel unwell after you get home it is important to

contact your local treatment centre straight away, or go to your local emergency department.

Feeling sick or being sick

This can happen after the treatment and may last a few days. Your doctor can give you anti-sickness medication to help with this. There are lots of anti-sickness medications available, so if your sickness is not controlled or continues, we can give you a different anti-sickness medicine that may suit you better.

Tiredness and generally feeling weak

NF2 may already make you feel tired, and you may find you need extra rest following your treatment.

Loss of appetite

You may find you do not feel like eating. The specialist nurse or dietitian can give you advice about eating well during your treatment and any dietary supplements that you may need.

Diarrhoea

This can be controlled with medication, but it is important to tell your doctor or nurse if the diarrhoea is severe or it continues for more than a day. It is important to drink more fluids if you have diarrhoea, so that you don't become dehydrated.

High blood pressure

Avastin can sometimes cause high blood pressure, which is why we monitor your blood pressure regularly. High blood pressure can usually be controlled by tablets, if needed.

Sore mouth and mouth ulcers

Your mouth may become sore during treatment or you may notice small ulcers. Drinking clear fluids, if you can, may help. You could also use a non-alcohol mouthwash.

Slow wound healing

Wounds can take longer to heal when you are taking Avastin, so it is important to let the doctor or nurse know if you have any concerns.

Constipation

Please let the doctor or nurse know if you become constipated, as they can give you advice about a high fibre diet and prescribe some laxatives if needed. If you have black, tarry (sticky) stools it is important to let your doctor know straight away.

Bleeding

Avastin can sometimes cause bleeding problems. It is important to let the doctor or nurse know if you take medication to thin your blood, such as aspirin or warfarin. If you cough up fresh blood or old blood (which will look like coffee grounds), it is important to let your doctor know straight away.

Blood clots

Avastin can cause an increased risk of developing blood clots. It is important to look out for and report straight away any chest pain, breathlessness, or red and painful swellings in an arm or leg. Do let the doctor or nurse know if anyone in your family has ever had a blood clot.

Lower resistance to infection

This is also called neutropenia and can develop if the treatment lowers the level of white cells in your blood, making you more prone to infection. It is important to contact your treating doctor or nurse straight away if your temperature goes above 38°C (100.4°F), or if you suddenly become unwell even if you do not have a temperature.

Changes in the way your heart works

This is very rare, but it is important to let the doctor or nurse know if you have any breathlessness, chest pain or ankle swelling.

Changes in the way your kidneys work

The treatment can sometimes affect the kidneys, so you will have regular urine tests during your treatment to check your kidneys are working well.

Parenthood

Avastin cannot be given during pregnancy. It is important not to become pregnant or father a child whilst receiving Avastin, as not enough is known about how the treatment would affect a developing baby. Breastfeeding should be discontinued during and for six months after treatment.

Contraception

It is important to use an effective method of contraception both during your treatment and for at least six months afterwards. You can ask your treating doctor or nurse for more information about this.

Other medications

It is important to let the treating doctor or nurse know the medications you are taking, including any over the counter or herbal remedies. This is to make sure that they don't have any reactions with Avastin.

How to contact the NF2 team

If you need further information, you can contact the Oxford NF2 Team by phone, text or email:

Telephone: **01865 231 741**
(Monday to Friday, 9.00am to 4.00pm)

Mobile: **07747 795 588**

Email: **nf2@ouh.nhs.uk**

Alternatively you can visit our website:

Website: **www.ouh.nhs.uk/nf2**

NF2 Specialist Nurse in Southampton:

The Southampton based Specialist Nurse is part-time and can be contacted from Monday to Thursday, between 8.00am and 4.30pm.

Telephone: **02381 204 973**

Mobile: **07747 837 593**

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

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March 2016
Review: March 2019
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