

MIBG (meta-iodobenzylguanidine) therapy

This aim of this leaflet is to help answer some of the questions you may have about mIBG therapy. It explains the benefits, risks and alternatives of the procedure as well as what you can expect when you come into hospital.

If you have any questions or concerns, please do not hesitate to speak to a doctor or nurse caring for you. Contact details are provided at the end of this leaflet.

What is mIBG therapy?

Meta-iodobenzylguanidine (mIBG) is the name of the chemical we use to treat a group of cancers called neuroendocrine tumours. These include phaeochromocytoma, paraganglioma, medullary thyroid, and carcinoid tumours.

Before we use the mIBG it is attached to iodine-131, a form of iodine which is radioactive. The mIBG is transported via the bloodstream to the sites of cancer where it is absorbed into the tumour cells. The iodine-131 delivers radiation to the cancer cells and kills them.

What are the benefits – why should I have mIBG therapy?

You have been diagnosed as having a neuroendocrine tumour and the diagnostic scan you have already had shows that you should respond well to this treatment.

The aim of the treatment is to slow the growth rate of the tumour, possibly shrink the size of the tumour, and reduce any symptoms associated with the tumour. This treatment has been used successfully in the management of the neuroendocrine group of cancers for many years.

Are there any side effects?

MIBG therapy is not given during pregnancy as it can harm the developing foetus. All women of child bearing age are therefore asked to provide a sample of urine to ensure that they are not pregnant when the treatment is given. If you are breastfeeding, you should tell your doctor so that you can discuss stopping this before you have therapy.

You may experience some nausea (sickness) following your treatment. You will be given anti-sickness medicine before you receive the treatment, and will also be given anti-sickness medicine to take home with you. This should be continued until the nausea settles, usually after a few days.

You may experience discomfort at the site of the tumour and depending on your tumour type, you may have some brief periods of flushing where you become very warm and your face may go red. This typically lasts for only a few minutes. You may also experience fatigue for up to two weeks after therapy.

The side effects from the radiation dose to your body can affect bone marrow cells, which may become quite low in number. Although you may not feel any different, this will be picked up from your blood test results. Further treatments may need to be postponed until your blood cell numbers are the same as they were before the therapy. Your doctor will discuss this with you.

Is there alternative treatment available?

There is more than one type of treatment for neuroendocrine tumours, including doing nothing. Treatment options are:

- Medicines for pain relief.
- Somatostatin analogues – these medicines, given by injection, are used for more specific symptom relief. They have been shown to help stabilise disease over a longer term.
- Interferon alpha – this medicine, given by injection, may help to stop tumour growth and improve symptoms.
- Surgery – if the tumour is accessible, this will reduce the tumour size and alleviate symptoms.
- Chemotherapy – if the tumour is of a type that responds to chemotherapy, this may be used to reduce tumour size and improve symptoms.
- Radio-embolisation or chemo-embolisation – these procedures reduce blood flow to the tumour by blocking the blood vessels that supply it. This may help to stop the growth of the tumour.
- Radiofrequency ablation – this is a procedure carried out under general anaesthetic. The procedure uses heat to surgically remove superficial tumours in the liver.
- Other radionuclide targeted therapies.

If you choose not to have mIBG therapy, your consultant will discuss these treatment options with you.

How can I prepare for treatment?

During treatment, small amounts of the iodine-131 can detach from the mIBG. If this happens, the 'free' iodine-131 is then absorbed by the thyroid gland and can cause damage. We will ask you to take a medicine called potassium iodate one day before and then daily during the treatment. This medicine will stop the thyroid taking up the radioiodine while the treatment takes effect. There are no known side effects, but if you know that you have reduced kidney function you should mention this to your doctor.

We also need to know about any other medicines you are taking or have been given, even if they are over-the-counter medicines you have bought yourself. These may affect the way the MIBG therapy works.

You should prepare to stay in hospital for at least four nights after the therapy so that you pass on as little radiation as possible to others. You will need nightwear and toiletries, but you should not bring large amounts of money or valuables into hospital with you. For more details about coming into hospital, ask for a copy of our leaflet, **Preparing for your inpatient stay at Guy's Hospital**.

Asking for your consent

We want to involve you in all the decisions about your care and treatment. If you decide to go ahead, you will be asked to sign a consent form. This confirms that you agree to have the procedure and understand what it involves. You should receive the leaflet, **Helping you**

decide: our consent policy, which gives you more information. If you do not, please ask us for one.

How is the treatment given?

You will be asked to come to the nuclear medicine department in the morning on the day of your therapy for a final discussion and to sign a consent form. We will escort you to Sarah Ward where a cannula (small plastic tube) will be placed in a vein your arm and you will be given medication to prevent nausea and vomiting. The mIBG therapy will then be given intravenously (into your vein) over approximately 45 minutes through the same cannula.

What happens after treatment?

Once the therapy has been given, you will need to stay on Sarah Ward for a minimum of four nights to allow the radiation to reduce to a level that is safe for you to go home. The time staff stay with you will be limited. They will visit you at least every four hours and contact you by telephone every hour to ensure that any needs you have are met. Staff will wear gloves, an apron and overshoes to prevent any transfer of radiation. You will be able to contact the staff using a call button or telephone if you need them.

On the day of your planned discharge you be asked to return to the nuclear medicine department (Sarah Ward) for a post-therapy scan. The scan may take up to two hours and will be similar to the one you had to check that mIBG therapy was suitable for you. The physics team will monitor you to assess your radiation levels and advise you of the precautions you need to take when you leave hospital. These precautions are necessary to reduce the radiation dose to other people with whom you come into contact.

Further treatments

For most people, three treatments are given 12 weeks apart, depending upon the effects of the therapy on your blood cells and kidney function. Your consultant or clinical nurse specialist will discuss this with you.

After you have gone home

You will be asked to have a blood test every two weeks for eight to ten weeks. This is to check the effect the therapy has had on your blood cells and kidney function. For convenience this will be arranged with your GP. Your clinical nurse specialist will contact you on receipt of the blood test results to answer questions and offer any necessary support. For at least six weeks after therapy, you should tell any nurse, doctor or pharmacist that you visit that you have received mIBG therapy.

A reliable contraceptive should be used until all treatment has finished and for at least six months afterwards. Men are advised not to father a child for the same period. Your doctor or clinical nurse specialist will discuss this with you.

Appointments at King's

We have teamed up with King's College Hospital in a partnership known as King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at King's. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals.

Contact us

If you have any questions or concerns, please contact us one of the following numbers (Monday to Friday, 9am to 5pm):

Clinical nurse specialist	Nuclear medicine physicists	Nuclear medicine department
☎ 020 7188 6304	☎ 0207 188 3802	☎ 020 7188 4112
0791 7087 528		

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

Useful sources of information

Neuroendocrine Tumour Patient Foundation

w: www.netpatientfoundation.com

Macmillan Cancer Support

w: www.macmillan.org.uk

t: 0808 808 0000

Association for Multiple Endocrine Neoplasia Disorders (AMEND)

w: www.amend.org.uk

Further information

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 9am to 5pm, Monday to Friday

Patient Advice and Liaison Service (PALS)

To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

t: 020 7188 8801 at St Thomas' t: 020 7188 8803 at Guy's e: pals@gstt.nhs.uk

Language Support Services

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

t: 020 7188 8815 fax: 020 7188 5953

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

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