

mIBG (meta-iodobenzylguanidine) therapy

This leaflet will answer some of the questions you 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 speak to a doctor or nurse caring for you (details at the end of this leaflet).

What is mIBG therapy?

mIBG is the chemical we use to treat a group of cancers called neuroendocrine tumours. These are a group of rare cancers that develop in the neuroendocrine system (made up of nerve and gland cells that produces hormones). 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 through 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.

The benefits of mIBG therapy

You have been diagnosed as having a neuroendocrine tumour and the diagnostic scan you have had indicates that you should respond well to this treatment. The aim of mIBG therapy is to slow tumour growth and reduce symptoms associated with it. It is typically given in 3 cycles, 12-16 weeks apart. This treatment has been used successfully in the management of the neuroendocrine group of cancers for many years.

The side effects of mIBG therapy

mIBG therapy is not given during pregnancy as it can harm the developing foetus. All women of child bearing age are asked to provide a sample of urine to make sure 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 (feeling sick) after 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 2 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.

Are there other treatment options?

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

- medicines for pain relief.
- surgery – if the tumour is accessible, this will reduce the tumour size and ease symptoms.
- chemotherapy – if the tumour is 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 such as lutetium-177 DOTA-octreotate
- palliative care. After fully discussing all your treatment options, you may decide you prefer not to have any active treatment, or your referring team may feel that active treatment will not help you. In this case, they can refer you for palliative care near your home. This supports you and helps to ease your symptoms, but it will not cure you. You can also have palliative care with some treatments.

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

How you can prepare for treatment

During treatment, small amounts of the iodine-131 can detach from the mIBG. If this happens, the 'free' iodine-131 is absorbed by the thyroid gland and can cause damage. We will ask you to take a medicine called potassium iodate the day before, and then each day 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 tell 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, or homeopathic medicines you have bought yourself. These may affect the way the mIBG therapy works.

You should prepare to stay in hospital for at least 4 nights after the therapy so that you pass on as little radiation as possible to others. For more details about coming into hospital, ask for a copy of our leaflet, **Having surgery at Guy's and St Thomas' Hospitals**.

When you leave hospital after mIBG therapy you will still have a small amount of radioactivity in your body. Your doctor will have discussed your home and working life after mIBG therapy with you, as well as the general ways for you to plan for your discharge. If you are still have questions about planning how you will manage, please call the nuclear medicine physicist team (details at the end of this leaflet).

Consent – asking for your consent

We want to involve you in decisions about your care and treatment. If you decide to go ahead, you will be asked to sign a consent form. This states that you agree to have the treatment and you understand what it involves.

If you would like more information about our consent process, please speak to a member of staff caring for you.

How the treatment is given

You will be asked to come to the Nuclear Medicine Department in the morning of the day of your therapy for a final discussion and to sign a consent form. We will take you to Sarah Ward where a cannula (small plastic tube) will be placed in a vein in your arm and you will be given medication to prevent nausea and vomiting (being sick). The mIBG therapy will then be given intravenously (into your vein) over about 2 hours through the same cannula.

After treatment

Once the therapy has been given, you will need to stay on Sarah Ward for at least 4 nights to let the radiation 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 4 hours and contact you by telephone every hour to make sure 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 will be asked to return to the Nuclear Medicine Department for a post-therapy scan. The scan may take up to 2 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 check your radiation levels and tell you of the exact precautions you need to take when you leave hospital. These precautions are necessary to reduce the radiation dose to other people who you come into contact with.

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 (CNS) will discuss this with you.

After you have gone home

You will be asked to have a blood test every 2 weeks for 8-10 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 CNS will contact you when they get the results of the blood tests to answer questions and offer any necessary support. For at least 6 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 6 months afterwards. Men are advised not to father a child for the same period. Your doctor or CNS will discuss this with you.

Useful sources of information

Neuroendocrine Tumour Patient Foundation, [w: www.netpatientfoundation.com](http://www.netpatientfoundation.com)

Macmillan Cancer Support, [w: www.macmillan.org.uk](http://www.macmillan.org.uk), [t: 0808 808 0000](tel:08088080000)

Association for Multiple Endocrine Neoplasia Disorders (AMEND), [w: www.amend.org.uk](http://www.amend.org.uk)

Contact us

If you have any questions or concerns, please contact us, Monday to Friday, 9am-5pm:

CNS, [t: 020 7188 6304](tel:02071886304) / [0791 7087 528](tel:07917087528)

nuclear medicine physicist, [t: 020 7188 3802](tel:02071883802)

Nuclear Medicine Department, [t: 020 7188 4112](tel:02071884112).

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [w: www.guysandstthomas.nhs.uk/leaflets](http://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](tel:02071888748), 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](tel:02071888801) (PALS) [e: pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

[t: 020 7188 3514](tel:02071883514) (complaints) [e: complaints2@gstt.nhs.uk](mailto: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](tel:02071888815) [e: languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

NHS 111

This service 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](tel:111) [w: www.111.nhs.uk](http://www.111.nhs.uk)

NHS website

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

[w: www.nhs.uk](http://www.nhs.uk)

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