# Information for patients having PRRT (Peptide Receptor Radionuclide Therapy)

Leicester Neuroendocrine Service

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Information for Patients

### What is PRRT and how does it work?

Peptide Receptor Radionuclide Therapy (PRRT) is a form of highly targeted radiotherapy. A drug containing somatostatin (a hormone) and a radioactive substance known as Lutetium –177 (Lu– 177) is injected into your vein. This binds itself to cells within your body called neuroendocrine cells and delivers a dose of radiation directly to the cancer cells and destroys them.

# What is the aim of PRRT?

The aim is to stop or slow down the tumour's growth and to improve your quality of life by controlling symptoms and potentially improving your overall survival.

# Am I suitable for this therapy?

If your medical team feel that your neuroendocrine tumour is not responding to other therapies and surgery is not possible, then this treatment may be offered to you. However, you need to be aware that:

- You will have had an octreotide scan to assess your disease and your medical team will discuss this with you and whether your tumour is likely to respond to PRRT.
- Your medical team may feel you are not fit enough to receive the therapy and will discuss this with you.
- This therapy cannot be given to pregnant or breastfeeding patients, due to the effects that radiation therapy can have on a foetus or baby.

#### Health information and support is available at www.nhs.uk or call 111 for non-emergency medical advice

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk



- Your kidneys and bone marrow need to be healthy, as the therapy can cause problems with your kidneys and blood. These will be regularly monitored before and after any treatment.
- If you suffer with incontinence, management of your body's fluid may lead to an increased radiation risk, for yourself and others taking care of you, which may exclude you from the therapy.
- If you have had already had four cycles of Peptide Receptor Radionuclide Therapy (PRRT) you may not be suitable to have more.
- The treatment might be considered inappropriate if you have another malignant tumour, unless you have been in remission for five years.-

# What are the possible side effects?

- Feeling sick and vomiting, particularly immediately after the therapy. You will be given medication to help to relieve this.
- An increase in pain for a number of days after the treatment. We would encourage you to take your prescribed pain killers during this time and in some situations, you might be prescribed a low dose steroid to reduce any inflammation.
- An increase in symptoms that you have previously been having: for example diarrhoea or sweating for a day or so.
- A small amount of hair loss during the treatment but this will regrow once the treatment is finished
- You may feel more tired than normal.

# PRRT, pregnancy, breastfeeding and conception

As the therapy emits radiation, it is not given during pregnancy. Patients with a female birth sex between the ages of 12 and 55 will be required to undertake a urine pregnancy test on the day of treatment, unless there is a medical reason that they are unable to become pregnant. These tests can miss pregnancies in their earliest stages. If you are a patient with a female birth sex between the ages of 12 and 55, you are therefore advised to abstain from any sexual activity in the fifteen days prior to treatment, to ensure your treatment is safe.

All patients—male and female—must avoid becoming pregnant or conceiving a child from the first treatment until six months after the last treatment. Effective contraception must be used.

Breastfeeding patients will need to stop some weeks before treatment starts, as the radiation can accumulate in breast milk, which will increase the patient's radiation dose and pass radiation on to the infant in breast milk. Please speak to your referring consultant for further information.

# How many times will I have PRRT?

This therapy is usually given in four cycles, eight to 12 weeks apart. You may need to stay in hospital overnight after each therapy. This will be discussed in a consultation with nuclear medicine.

# What happens before I have PRRT?

- You will come to the hospital to talk through the treatment and your options in detail with your medical team.
- You will need to give your written consent.
- If you are having any somatostatin injections, whether in the hospital or out in the community, it is important that we know the date of your last injection. Giving the PRRT needs to be planned when your injection is due. If you are having short-acting somatostatin injections, these should not be given for 12 hours before and after PRRT.
- You will have routine blood tests and a general health assessment before each cycle. It is important to let us know what medicines you are currently taking.
- Initially you may need to stay overnight in hospital after the therapy, usually for just one night
- During and after your treatment, you will not be allowed visitors to your room in hospital, because of the radiation risk.
- Patients with a female birth sex, aged 12-55 must perform a pregnancy test before each therapy is given.

# How is PRRT given?

When you arrive on the ward in the Osborne Building at Leicester Royal Infirmary, you will be directed to your allocated side-room. The treatment takes about four to five hours to give to you.

You will have two thin plastic tubes (cannulae) put into veins in your arms. You will receive an injection through this to stop you feeling sick.

An infusion of amino acids will be given to help to protect your kidneys. This will be started at least half an hour before the Lutetium infusion and will continue to run for several hours after the Lutetium treatment has finished. The Lutetium treatment takes half an hour to be given.

The tubes are then removed from your arms. You must remain in the side room and use the allocated bathroom facilities as needed.

Nuclear Medicine staff will take readings of how radioactive you are after the Lutetium infusion and before you use the bathroom.

After treatment it is important that you follow these instructions, to reduce radiation exposure to people you see regularly for their protection:

- Children under 5 years and pregnant women-: avoid contact for the next 20 days.
- Children between 5—18 years:

First 7 days - limited contact for up to 2 hours per day separated by a distance of at least 1 metre (approx. adult arms length). Sleep in separate rooms.

After 7 days and up to day 20 - contact needs to remain at a distance of at least 1 metre but no time restrictions. Sleep in separate rooms.

After 20 days – no restrictions

#### Adults

For the first 15 days any contact should be at a distance of at least 1 metre (approximately one adult arm's length)

Sleep in a bedroom on your own for 20 days.

#### Other advice for the first seven days after treatment:

- Drink plenty of water to pass urine every hour on the day of treatment and on the following day.
- Try to ensure that your bowels are opened daily.
- Use the toilet in a sitting position and use toilet paper every time.
- **Always** flush the toilet **twice after use for one week** following therapy and wash hands thoroughly.
- Discard any tissues that contain bodily fluid immediately after use.
- Limit each journey on public transport to **no more than one hour for the first week** following therapy.
- Avoid conceiving a child or becoming pregnant from your first treatment until six months after your last treatment. Use effective contraception during this time.

# What happens when I go home?

Following the treatment:

- you will have blood tests and a scan to help us assess your response to the treatment.
- you will need to follow the radiation precautions given to safeguard others from any exposure to radiation.
- you will be given a yellow radiation precautions card by nuclear medicine to carry with you at all times for three months following each treatment.
- you will have blood tests every two weeks, for eight to 10 weeks, to check that your body has had no ill effects from the therapy.
- your clinical nurse specialist (key worker) will be in contact about your blood test results and to talk to you about any other concerns you might have about your therapy or neuroendocrine tumour.
- you will receive further dates for treatment and also follow-up scans to assess how well the therapy has worked for you. These will be discussed with you in clinic by your consultant.

It is very important to keep your appointment dates. If you do not attend this can be costly as the medications are prepared for your use only and will have to be destroyed.

Please tell your nurse specialist, the oncology team or the Nuclear Medicine Department at the Leicester Royal Infirmary as soon as possible if you are unable to attend your appointment.

# When can I go back to work?

This depends on the type of work you do and if you are able to comply with the radiation restrictions provided. Please discuss this with your consultant before PRRT starts.

After therapy, for at least the next month you should inform any doctor, nurse or other healthcare professional that you come into contact with, that you have been treated with PRRT. Your precautions card will have the contact details of Nuclear Medicine Physics if they have any questions.

# In case of a medical emergency:

Please ensure that a family member advises the health care team treating you to contact:

Nuclear Medicine Physics: 0116 258 5627 or 0116 258 6331

Emergency Physicist on 0300 303 1573 (out of hours).

In the unlikely event of death within 1 month of the date of treatment please ensure that a family member advises your treating physician. The treating physician is advised to contact the coroner, and provide contact details of Medical Physics (above). Any arrangements for cremation must be postponed for 28 days following treatment.

# Being out and about after treatment

For some time after your treatments you may find that the low level of radiation in your body may cause security scanners to alarm (for example at an airport, public event or going into some public buildings). We advise you carry the yellow instruction card for up to three months after treatment, so that you can show it to any officials and advise them to use the contact details, if required.

### Sources of information and support

Macmillan Neuroendocrine Nurse Specialist (key worker)

Work mobile 07950 888023

Hours of work Monday to Friday 08.00am—04.00pm

Nuclear Medicine Department: To contact us about these instructions please telephone or email Nuclear Medicine Physics: 0116 258 5627 or 0116 258 6331 or <u>NMPhysics@uhl-tr.nhs.uk</u>

#### Macmillan Information and Support Centre

Osborne Building, Leicester Royal Infirmary, LE1 5WW Opening hours: Monday to Friday from 9.30 am to 4.30 pm Telephone: 0116 258 6189 Email: cancerinfo@uhl-tr.nhs.uk Website: www.leicestershospitals.nhs.uk

#### **NET Patient Foundation**

Offers information and advice to those affected by neuroendocrine tumours. Freephone:0800 434 6476 Website: www.netpatientfoundation.org

#### Macmillan Cancer Support

LEICESTER'S

Freephone:0808 808 00 00 Website: www.macmillan.org.uk

#### **Cancer Research UK**

Ask specialist nurses about anything to do with cancer.

Freephone:0808 800 4040 Website: www.cancerresearchuk.org

اگر آپ کو یہ معلومات کسـی اور زیان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔ علی هذه المعلومات بلغة أخری، الرجاء الاتصال علی رقم الهاتف الذي يظهر في الأسفل જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હ્યેર, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ `ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ। Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk

Leicester's Hospitals is a research active trust so you may find research happening on your ward or in your clinic. To find out about the benefits of research and become involved yourself, speak to your clinician or nurse, call 0116 258 8351 or visit www.leicestersresearch.nhs.uk/ patient-and-public-involvement