**Admission for treatment with Lutetium/Yttrium DOTATATE**

Please read this information carefully and bring it with you when you come to hospital

Please report to the admissions desk, Oak Road entrance, when you arrive

**Introduction**

We hope that this leaflet will answer any questions you may have about Lutetium/Yttrium DOTATATE treatment. When you have treatment there are some extra preparations and precautions which we would like to explain to you.

**What are the benefits of treatment?**

As your doctor will have explained to you, you will be receiving radioactive Lutetium/Yttrium DOTATATE as your treatment. DOTATATE is a chemical which is taken up by certain neuroendocrine tumours. It is given to you as an intravenous infusion (into a vein) and is absorbed by the tumour. By combining DOTATATE with radioactive Lutetium or Yttrium, radioactivity can be concentrated into the tumour. The aim is to improve your symptoms although the long-term effectiveness will vary from person to person. Your doctor will have discussed what the treatment will involve and the benefits, risks and alternatives. We will ask you to sign a written consent form before the treatment.

**What is Lutetium/Yttrium DOTATATE?**

It is a radioactive labelled peptide*. This peptide binds to certain receptors on cells called somatostatin-receptors. Previous studies will have already shown that your tumour has these receptors. Combining radioactivity with agents that target specific tumour cells is an established technique to treat tumours and is sometimes known as Targeted Therapy: this therapy is one of these techniques.

**Is there any preparation for the treatment?**

Before you have treatment you will have some tests to make sure that it is a suitable treatment for you. These involve a series of scans, using a gamma camera, taken when you have been given a very small dose of radioactive peptide (Octreotide), given as an injection. These scans take place over two days; you will have them as an outpatient which means you need to visit us each day. We use these scans to see how much peptide your tumour takes up over time. Your doctor will then discuss the results of these scans, if this treatment is appropriate for you and, if so, they will arrange for your admission.

Before your admission you will also undergo a CT scan, which we use as a base line to monitor the effects of treatment and also a test called a GFR test which is a standard test to assess your kidney function.

**What about my medications?**

Some drugs can interfere with the way that DOTATATE is taken up. Your doctor will check which medications you are on and advise you which, if any, should be stopped before treatment. You must make sure that you provide a complete list of all medications you are taking.

*A peptide is a fragment of a protein
You may be on a monthly injection of somatostatin (sandostatin, LAR/lanreotide). Your last injection must be at least 4 weeks prior to this treatment.

Please bring with you any tablets and medicines you are taking, including any you have bought from a chemist, so your doctor can check them. Please bring enough with you for the duration of your stay.

**Should I tell anyone if I am pregnant or breast feeding?**

**Yes please, this is very important.**

If you are a woman you will be asked:
Are you or might you be pregnant? Are you breast feeding?

You will be asked this before you have either the scans or the treatment.

If you are pregnant, or even if you think you might be, the tests and the treatment must be delayed.

If you are breast feeding, you must stop completely before having the treatment and you must tell us about this before you have the tests.

**These precautions are to protect your baby.**

Also we must advise you not to become pregnant until at least 6 months after you have had the treatment. The treatment should not affect your fertility.

Men are advised not to father a child for the same period.

If you are sexually active it is very important that you use effective birth control after treatment.

**Where will I be staying during my treatment?**

On the day before treatment you will be admitted to our specialist unit at The Christie. You will have your own room and bathroom which only you must use during your stay, as some of the radioactivity is passed out in your urine. The room is very comfortable and has a telephone, television set and DVD player.

Before your treatment a member of staff from the Nuclear Medicine Department will visit you to help you settle in. They will be able to explain more about your stay and answer any questions about what you can and cannot do afterwards.

**After the treatment, you must stay in your room for up to two days. You will read more about this later on.**

**What shall I bring into hospital with me?**

As little as possible.

Because of the treatment you are having, any personal possessions you bring in with you may become contaminated with radioactivity, and would have to be left behind until they are safe for you to take home. We do have some comfortable clothes for you to wear whilst you are in hospital if you choose and night clothes and towels will be provided. If you wish to wear your own clothes please bring old ones. We also recommend disposable toiletries and underclothes.
There is a small locker in your room. Any clothing needed for going home must be kept in the locker in a sealed bag. Please do not bring large amounts of money or valuables. You may bring fruit, sweets, biscuits and squash, books, DVDs and mobile phones but please remember that these items may have to stay with us after you have gone home.

Everything in your room will be checked before you leave. If there is anything you wish to take home it must be checked for levels of radioactivity. You will be asked to sign a form on admission which serves as a receipt for your belongings and tells us if you wish them to be kept or disposed of on discharge.

**What other things do I need to know?**

- If you wear contact lenses it is best not to use them whilst you are having the treatment. Please bring some glasses.
- The Christie has a strict non-smoking policy. If you are a smoker you will not be allowed to leave your room for a cigarette during your treatment. You can contact the smoking cessation service at The Christie on 0161 446 8236 or see your GP to arrange for nicotine patches if you think this will help.
- There will be a telephone in your room for making and receiving calls. It uses a phone card that you can buy before your treatment. Please use this to speak to your family and friends. You may also bring in a mobile phone to use just within the room
- We will enclose a questionnaire for you to fill in and return to us at least 1 week before your treatment. Please make every effort to complete it. It helps us to understand your home situation and plan ahead to make your treatment as trouble-free as possible.

**How is the treatment given?**

Having the treatment is very straightforward and in total lasts about 4 to 5 hours.

You will come to the Nuclear Medicine department on the morning of your treatment. We will ask you to have your height and weight measured and we will also take your blood pressure. Before the treatment you will be given an anti-sickness injection to prevent any problems during treatment. The treatment will then be given into a vein in your arm. In addition to this you will also have drips into your arms to give you some special fluids that will help to protect your kidneys from the radiation. These drips shouldn't be painful at all; if you notice that your arm is sore, red or burning please tell the staff straight away.

**Are there any side effects?**

There is a possibility you could feel sick. These effects are usually mild and only last for a few days. Please tell the ward staff about this immediately, so that they can give you some medicines to prevent it becoming too uncomfortable.

Treatment can affect blood counts, and most patients experience varying degrees of anaemia, low white cells, or low platelets. Sometimes it is no worse than a few days of tiredness.

**If you do feel sick at all while you are in hospital, or have any other problems, please tell the staff on the ward straight away**
Why do we mention precautions?
Because treatment is radioactive, you will be radioactive for a while after the treatment. The treatment is for your benefit, but you will have to stay in hospital, in isolation, until the amount of radioactivity has fallen to a safe the right level.

The precautions which are described in this booklet are intended to protect other people from the radiation, particularly pregnant women and young children. It makes sense to reduce everyone’s exposure to the radioactivity. This advice is to protect other people, especially your own family, from the radiation.

What precautions should I take whilst in hospital?

- Drink plenty of fluids and shower freely.
- Suck boiled sweets after treatment to prevent a dry mouth.
- Rinse your washcloth and toothbrush thoroughly.
- Flush the toilet twice after use. To avoid any splashes we ask gentlemen to sit down when using the toilet.
- Please use soft tissues rather than handkerchiefs and flush them down the toilet.
- If you experience prolonged constipation please inform the nursing staff.
- Wash your hands before eating, reading or handling items.
- Tell the nurses straight away if you have an accident with urine spillage or splashing.
- Although you are in a room on your own, the nursing staff will be in regular communication with you. They will bring and clear your meals, but will not make your bed. They are always available if you feel unwell.

How long will the radioactivity stay in my body?
The Lutetium/Yttrium DOTATATE will gradually disappear from your body, mainly in the urine. Also, because radioactivity decays, the amount remaining inside you will reduce each day. How long it takes to disappear varies from person to person. During your treatment we will be making measurements regularly to see how much activity is left in you. We will be able to predict when you can go home and the restrictions you need to follow.

How long must I stay in hospital?
The time you must stay in hospital will depend on how long the radioactivity stays in your body and who you live with. The average stay is one to two days but we cannot guarantee this.

Your family circumstances are important. If you live with young children it may not be possible for you to return to them straight away. Please contact us to discuss this if you have any concerns.

May I have visitors?
You are allowed visitors but there are some restrictions.

After you have your treatment, you must not have close contact with other people. No one may visit on the day of treatment. After that you may receive visitors following the instructions below.

The amount of space between you and your visitors must be a maximum. Visitors may sit in your room but not on the bed with you. They should sit behind the bed shield. You should not
have physical contact with your visitors or hand them anything such as food or drink. Visitors
should not use your bathroom or eat or drink any of your food. There are no set visiting hours.

It is important that children under the age of 18 and pregnant women are not allowed to visit
during this time.

**Are there any precautions when I go home?**

When you are ready to go home, we will give you a card with some instructions about contact
with people, and especially children. We hope that these precautions will not make life too
hard for you. We would rather you have the information in advance, so that you can discuss it
with your family if necessary. You may need to take some time off work and avoid public
transport and certain social activities.

**How can I reduce the radiation dose to other people?**

When you receive your instruction card, it will give you three dates, based on your
measurements taken during your stay.

- The first date is the time you can start using public transport and mix freely with adults.
  This can be up to 2 days from returning home
- The second date is when you may start having short periods of contact with children and
  pregnant women. This can be up to 4 days.

The third date is when you are free to resume all close contact with children. This may be as
long as 7 days.

**Until each date, you should follow the instructions on the card.**

**How may I travel home?**

We will advise you about this. It will depend on how much radioactivity is left in your body
when you go home. Generally, you may go home by private car or taxi, provided you are not
travelling with children or pregnant women.

You may be able to go home by public transport, if you would like to. Again, this depends on
the amount of radioactivity and also on the length of your journey. If we would rather you did
not take public transport, we will arrange alternative transport for you.

**What should I do at home?**

You will have a card or we will write the date when you can resume normal activity.

Until then:

- Avoid close contact with other people, but especially with children and pregnant
  women.
- If you look after young children, you should if possible make arrangements for them to
  be cared for by others.
- Minimise contact with household pets.
- Avoid public places like shops, cinemas, public houses and public transport (after the
  journey home).
- Sleep alone if possible.
- Avoid kissing and/or sexual activities.
• Flush the toilet twice after use. Wash your hands thoroughly and rinse the basin thoroughly. If you have access to two toilets reserve one just for you.
• Make sure that no-one else uses your towels and face-cloths.
• Wash your towels and under-clothing separately.

Bathroom hygiene is the main way of avoiding contaminating other people.

When may I go back to work?
We will advise you when you can return to work. However, if you either:
• work with children, for instance as a teacher or a nurse
• have close contact with pregnant women at work
• work in the food preparation industry
• think that a small amount of radiation might affect your job (for instance, if you work in a hospital’s radioimmunoassay department, or a photographic studio),
then please let us know, as you may have to stay away from work for a little longer.
If in doubt, please discuss this with us.

Can I travel?
You will be given a date when it is safe for you to use public transport. However if you are planning to travel abroad, particularly on a long flight, please inform us. There are two reasons for this.

Firstly, we need to ensure that it is safe for you to sit close to someone for the length of your flight. Airplane seats are often close together so we like to check that everything is safe.

Secondly, many airports and ferry terminals now have radioactivity detectors as part of their security systems. In recent times there have been a few cases where people treated with targeted therapy have triggered these detectors even though the level of activity in them is well below the public limit. We are happy to provide a letter explaining your treatment that can be produced in the event of any problems.

Will I have to have another scan or treatment?
As well as monitoring the radioactivity, we need to perform a series of scans to see the distribution of the treatment in your body. These scans will be performed immediately after your treatment and again 24 hours later. We also need to perform the scans at 3 days and 6 days. The scan is performed using a gamma camera and is very similar to the octreotide scan you had before your treatment.

If you live with young children we will use the monitor readings when you come for these scans to confirm when it is safe for you to be with them full time.
Contact details

Medical Oncology:

Prof Juan Valle
Consultant medical oncologist
0161 446 8106

Dr Richard Hubner
Consultant medical oncologist
0161 446 8199

Dr Was Mansoor
Consultant medical oncologist
0161 446 3209

Ms Lynne McCallum
Nurse Specialist
0161 918 7965

Nuclear Medicine:

Dr Prakash Manoharan
Consultant radiologist
0161 446 8246

Dr Jill Tipping
Clinical scientist
0161 446 3078

Nuclear Medicine Department
0161 446 3945 or 3946

We hope that this leaflet has answered most of your questions. If you have any more questions, or if there is anything about the treatment you do not understand, please ask.

Sources of information and support

NET Patient Foundation  www.netpatientfoundation.org
Macmillan Cancer Support  www.macmillan.org.uk
Cancer Research UK  www.cancerresearchuk.org/
National Electronic Library for Health - Cancer  www.libraries.nelh.nhs.uk/cancer/
North of England NHS Cancer Network
www.cancernorth.nhs.uk/cancertypes/NeuroendocrineTumour/WhatisaneuroendocrineTumour
National Cancer Institute USA  www.cancernet.nci.nih.gov/
Cancer Information Centre at The Christie (Withington)  0161 446 8100

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.
We try to ensure that all our information given to patients is accurate, balanced and based on the most up-to-date scientific evidence. If you would like to have details about the sources used please contact patient.info@christie.nhs.uk

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For more information about The Christie and our services, please visit www.christie.nhs.uk or visit the cancer information centres at Withington, Oldham or Salford.

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