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# PRRT

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## A treatment for neuroendocrine cancers

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This booklet was produced by Unicorn Foundation  
NZ in partnership with Auckland DHB



Unicorn  
Foundation

*Seeking the cure for  
Neuroendocrine Cancers*

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## Introduction

This booklet provides treatment information about Peptide Receptor Radionuclide Therapy (PRRT) for patients with NeuroEndocrine Tumours (NETs). We hope you find this a helpful and informative guide for understanding PRRT treatment.

If there is any information in this guide that you do not understand please feel free to discuss it with a member of your medical team. We also encourage you to discuss any information you find on the internet with your healthcare team.

This booklet was created through funding from Unicorn Foundation NZ, the national advocacy group supporting people with neuroendocrine cancer in New Zealand. This booklet and other NET resources are available online at [www.unicornfoundation.org.nz](http://www.unicornfoundation.org.nz).

### Not every person with a NET is a suitable candidate for PRRT

Patients should ideally be treated within a specialist multidisciplinary team (MDT). Each patient will have an individualised treatment plan: there are a number of options available, depending on the type and location of your NET, and your general well-being. The aim of this booklet is to help with your understanding of PRRT, which is just one of the treatment options for NET cancers.

## How cells function

Almost all cells in the human body have receptors on their surface that influence how they function. A receptor is like a switch that turns on or off a particular function of that cell. The switch is activated by chemicals, hormones and many drugs, which stick to the receptors and sometimes enter the cell too.

Some NETs have special receptors on their cell surfaces called somatostatin receptors (SSRs). The name comes from the hormone called somatostatin, which sticks onto these receptors and then enters the neuroendocrine cell enabling it to function normally. Without somatostatin attaching to SSRs, the cell may be influenced to produce large amounts of unwanted hormones like serotonin.

## The role of somatostatin receptors

Manufactured or “man-made” versions of somatostatin are called somatostatin analogues. These drugs are designed to mimic somatostatin by sticking to the receptors and being absorbed into the neuroendocrine cells. Drugs like Octreotide and Lanreotide are somatostatin analogues that stick to these receptors on neuroendocrine cells and help to switch off the production of hormones.

When these drugs are tagged with a radioactive isotope it is possible to use special scanners to detect the radioactive isotopes. These pictures or scans show the distribution of affected cells around the body. The most accurate scan is the GaTate PET scan which uses radioactive <sup>68</sup>Gallium. Some centers in New Zealand still use the Octreoscan which uses radioactive <sup>111</sup>Indium. With these scans doctors can look at images and see possible locations of NETs all over the body.

The radioactive isotopes used for these scans are low dose. If the drug is tagged with higher doses of radiation the cells absorb this high dose radiation and are killed. This is how PRRT works.

## **Finding out if your NET is suitable for PRRT**

To decide whether this therapy is suitable, you will need to have a GaTate PET scan. Intermediate and higher grade NET patients will also need a FDG PET scan. The results of these scans will indicate whether or not your NET has enough receptors present on tumour cells, and whether this sort of therapy would be an option.

## **When is PRRT treatment considered?**

If your scan shows that a significant number of tumour cells have somatostatin receptors then radionuclide therapy is likely to be a good option for you. It is given to try either to relieve your symptoms and/or shrink the tumours. The initial or first course of PRRT treatment is usually four treatments approximately eight weeks apart. Further maintenance treatments can be given if your disease responds well initially but recurs later. Each patient's case is assessed based on their disease and symptoms.

You will only be offered PRRT if your scan demonstrates adequate concentration and suitable distribution of the somatostatin receptors, and the nuclear medicine specialist estimates that the potential benefits outweigh the risks of the treatment.

## **How is PRRT given?**

The PRRT process takes about four to six hours as an outpatient at the hospital. To start you will be given an amino acid infusion before and after the radioactive LuTate to help protect your kidneys. This amino acid is given intravenously over four hours and can cause nausea so you will receive medications to minimize this side effect. The radioactive LuTate treatment is given as a simple intravenous (IV) infusion over about 30 minutes. The distribution of the treatment dose is usually monitored or seen by a scan that you will have the day after the treatment.

Sometimes, the specialist may recommend that you receive a dose of chemotherapy which is expected to increase the effectiveness of the treatment. This additional chemotherapy is usually an oral drug treatment called Capecitabine, which can be given with or without another chemotherapy called Temazolomide. The schedule for when to start taking these drugs is recommended through your oncologist and nuclear medicine specialist liaising on the most effective treatment for you.

There are different types of PRRT treatments given around the world. ADHB uses Lutate, which is [177Lu]-DOTA-octreotate to treat NETs.

## Things to be aware of

You receive the radionuclide treatment through an IV cannula, or a Central Venous Access Device (CVAD) which is a catheter that can stay in your vein for weeks or months.

On the day of treatment the nuclear medicine specialist and nursing staff will complete admission procedures, answer any questions you may have, and will check your blood tests. After this, you will be given the radionuclide treatment. The staff can only stay with you for short periods of time to minimize their radiation exposure.

When you are discharged you are still radioactive. The nuclear medicine staff will discuss your lifestyle, and how to manage this and other issues such as travel, returning to work, pregnancy and contraception, and give you written instructions as a reminder. You will get specific advice, but to help you know what to expect we have some rough guidelines to follow in the next section. Please do not arrange long distance travel within 48 hours of your treatment.

If you have been prescribed somatostatin analogues you will need to stop this prior to having the diagnostic scanning procedure (24 hours prior for daily injections; 4 weeks prior for monthly injections). When the results of the scan are available you can discuss the images and the potential treatment options with the nuclear medicine specialist. If you proceed with PRRT you will need to stop your somatostatin therapy, just as you did prior to your scan. Immediately prior to treatment your general health, blood count, liver function and kidney function will be checked to make sure you are well enough to proceed with PRRT.

All females capable of being pregnant will need to have a pregnancy test on the day of treatment before PRRT is given.

You will need to be available for a few days, but will not need to be admitted for the whole time, so accommodation in the area is required and usually arranged by your local DHB. Where possible, this will be at Domain Lodge, just across the road from the hospital.

## What you need for treatment day

Please remember to bring with you:

- All your medications, prescriptions and appointments
- Information about diet restrictions
- A book, laptop or other entertainment
- Eat a light breakfast in the morning and pack some snacks for the day.

## Getting to your treatment

As a day patient it is best if the person who brings you in on the day does not stay with you the whole time. It is safe for them to drive you home. If you are given any sedative medication with the treatment you will NOT be able to drive, so please arrange to have someone with you who can accompany you home after treatment.

## Side effects of PRRT

Many patients experience temporary, short term side effects, and these may be similar to the effects of the chemotherapy:

- Increased pain or other symptoms following treatment (flare), often related to the location of your tumour. It is best to discuss these with the nuclear medicine specialist and ensure you have pain relief to help you through this time.
- Amino acid infusions may cause experience a temporary phlebitis (inflammation of the vein) at the site of the infusion. Occasionally a reaction such as a rash might also be seen.
- Most people will experience some nausea during infusion of the amino acids/ radionuclide. Medications will be prescribed and given in advance to help control this.
- Some patients experience temporary, mild hair loss or thinning after LuTate treatment.
- Lethargy or tiredness is often reported by patients following radiation treatment.

Serious side effects are extremely rare:

- The most frequent side-effect is a decrease of white blood cells and platelets. This does not occur in every patient and is temporary. If it occurs, further treatments may be modified to allow time for your blood counts to return to normal levels.
- A potentially more serious and possibly life-threatening blood condition which can occur is Myelodysplastic Syndrome (MDS), usually a pre-stage of leukaemia. This is known to be a risk with other radionuclide therapies but tends to happen only after multiple doses of therapy. Consequently the specialist will try to 'ration' your treatments to get the best benefit without unduly compromising your bone marrow.
- Patients with very extensive, diffuse liver metastases may experience a temporary deterioration of liver function in the weeks following the therapy.

## What follow-up do I need?

When you are discharged after each treatment you should have:

- A list of radiation safety instructions to follow when you return home
- An appointment for a scan within the next day or so
- Blood tests to check your progress over the next few weeks
- If you are on somatostatin analogues - organise to resume your treatment
- If you are on chemotherapy - appointments with your oncologist to complete this
- **Either** an appointment for the next treatment **or** diagnostic review with both imaging and blood tests approximately three months after your final treatment cycle (or as directed by your nuclear medicine specialist).

## Precautions to take at home after treatment

You will still be slightly radioactive when you return home and may need to restrict your contact with others, particularly children and pregnant women. Following treatment you will be given a written guide containing specific information, but generally the following applies:

Risk Group	Days	Instruction to be followed from the day of discharge:
Babies under 5 yrs and pregnant women:	3	Normal association with other people is quite in order, such as short trips on public transport, in your car, or at home.
Children 5-18 yrs:	1	<b>But please remember:</b> Do not spend unnecessary time in close proximity to others, particularly pregnant women or young children e.g. nursing or sleeping with children.
	1	If contact is prolonged (watching T.V., travelling) try to maintain a distance of about two metres (6 feet). Avoid long trips on public transport, or activities where you spend a long time sitting next to others, such as at the theatre or movies.
Partner or Carer:		
	> 6 weeks	Over the next few weeks, and even for as long as three months, there is a possibility that you may trigger a radiation detector at a security checkpoint, even though the radioactivity is at a low, safe level. Therefore you are advised to carry your discharge note with you at all times when travelling.

## Communicating with the health care team

Being diagnosed with cancer can be a confusing and frightening time for you and your loved ones. Although your healthcare team will do their best to support you, medical appointments can be stressful and it is worthwhile to be reminded of ways to get the most out of each appointment. A few things to keep in mind:

- The most important part of your healthcare team is YOU
- YOU know more about YOU than anyone else does
- Your doctor can help you more if you are an active partner in your treatment and you keep them fully informed of what has been going on for you

### Tips to help keep you communicate with your health care team

- Bring a trusted friend or family member with you to appointments if you can. If you are feeling anxious, you may not hear everything that's said, or ask all the questions you wanted to. It helps to have additional ears there to listen, and your guest may help to make sure your concerns are brought up.
- Try taking notes on how you are feeling, and take these notes into your appointments.
- Write down a list of questions you want to ask. If you don't understand the answers to any of your questions, don't be embarrassed to ask for the answer to be repeated or rephrased. Make sure you know who your point of contact is and how to get hold of them, in case you have questions later.
- Deciding on a treatment strategy can be difficult so encouraging your doctor to seek opinions from other specialists can be valuable. This is often done during discussion at the NET MultiDisciplinary Meeting (often referred to as MDM). Physicians are usually very open to this because they appreciate the fact that

making an effective treatment choice for people with NETs can be very challenging. You can always request that your case be discussed at an MDM.

- You have the right to know as much about your own prognosis as you wish and you have the right to know the overall treatment strategy, including what options are available to you if initial treatments do not work to stabilise your disease.
- You have the right to make decisions for yourself, even if the decision is against medical treatment or the decision is to end medical treatment.

## Living with a NET: Diet, Exercise and Psychological Support

### Diet

Dietary advice will vary from patient to patient since people with NETs have different symptoms. One general piece of advice is that all patients are encouraged to eat a varied and proper diet so that energy and nutritional requirements are met and weight is kept stable. When problems such as loss of appetite or diarrhoea occur this can be difficult. Sometimes talking with a dietician can be very helpful, which your specialist doctor or nurse can arrange for you.

### Exercise

Regular physical activity improves well-being, functional ability, muscular strength, and may counteract side effects of treatment. These factors in combination improve a patient's quality of life. In New Zealand some gyms offer cancer support programs to help maintain your well-being.

### Psychosocial Support

Being diagnosed with a cancer can change your view of life. Being diagnosed with a cancer can be a challenging life situation. For people with NETs that produce extra hormones, this can provide additional challenges as these can affect normal bodily functions. Having an understanding of your disease and its effects on your body can be helpful in developing coping strategies.

There are support people around to help you understand your disease. Sometimes it is helpful to talk with a counselor or psychologist to help you develop strategies for coping with your particular concerns.

### Relationships

A diagnosis of cancer can bring you closer to your family and friends, but it can also put increased pressure or strain on those relationships. You may feel like you're a burden or your NET has become such a focus of your life. Your supporters may want to try do something to help but are unsure of what/how to do so. Whatever your situation is, remaining honest and having open lines of communication can really help. Explaining what you need and getting issues out in the open without blame or criticism can help. Talking to your partner, family, children and friends about your diagnosis can be tough. Supporters often ask questions in different ways – we all process information differently and you may have to repeat information several times for them to understand your situation.

Make time to enjoy doing the things you have always enjoyed. You might have cancer but this does not need to define who you are.

## Further Support

This booklet was created through funding from Unicorn Foundation NZ, the national advocacy group supporting people with neuroendocrine cancer in New Zealand.

Unicorn Foundation NZ aims to provide support and accurate information to patients, families and medical professionals involved in NET cancer. Unicorn Foundation NZ provides one-on-one nurse specialist support to answer patient questions, and brings patients together online and face-to-face to help support from people who are facing similar challenges. Email [support@unicornfoundation.org.nz](mailto:support@unicornfoundation.org.nz) or visit the website [www.unicornfoundation.org.nz](http://www.unicornfoundation.org.nz).