



**NeuroEndocrine
Cancer** Australia

Living with a NET

The experience of living with an uncommon cancer, such as a NET, is not fully appreciated by most people in the medical and general community. Many patients have a physical and an emotional journey.

For most patients with NETs, their story can be divided into four chapters.

First chapter: Something feels wrong

This is the phase of knowing, or feeling, that something is wrong with their health. You may have periods of feeling well punctuated with episodes of symptoms or have symptoms that become more frequent. You visit their general practitioner many times with the vague symptoms of fatigue or ‘feeling just not right’. Your doctor may discuss irritable bowel; flushing/rashes or asthma, which mimic common conditions but actually are due to NET.

On average, NET patients see four to six different doctors (including specialists) over 4 to 7 years before the correct diagnosis is made.

Because of repeated misdiagnoses, patients may feel frustrated, confused, and at times depressed. Some lose faith in the medical system altogether. You may have spent considerable time and money seeking the correct diagnosis. Tragically, because NET patients visit their doctors on so many occasions, some are labelled as being mentally unstable or ‘hypochondriacs’.

Second chapter: Diagnosis

This is when a diagnosis of NET is finally made. Patients experience a range of emotions at this point.

- relief that the correct diagnosis has been finally made
- anger at the medical community for the delays and misunderstanding in the diagnosis
- confusion
- fear and hopelessness about what the future holds.



The treating doctors can present a confusing picture of NETs to patients. The word cloud (see image) captures many of the ways the medical community currently views NETs.

This time can be very difficult. Despite the fact that they have a diagnosis, many patients are inadequately treated, mismanaged and given incorrect information by doctors who do not understand NETs. This is understandable given that NETs are an uncommon cancer and many doctors would not have seen a patient with NET in their practice before and may not know where or who are the 'experts' in treating this uncommon cancer.

Because of the different types of NETs—functioning or non-functioning, their location and grade (e.g. slow growing or aggressive), the hormones that they may secrete and whether they have spread—the medical and surgical options for managing each patient's NET are specific to that patient.

A treatment plan that is clinically suitable for your NET requires assessment and review of your medical history by a NET specialist with access to a NET multidisciplinary team.

Many clinical studies demonstrate that NET patient care and long-term outcomes are improved when managed by a specialised neuroendocrine multidisciplinary team (MDT). It is critical for NET patients to have access to such people and teams to ensure that they are being managed appropriately and receiving the best available treatments.

You may feel uncomfortable asking your doctors for a 'second opinion' to be provided by a NET specialist; however, doctors are usually agreeable to this because they appreciate the fact that making an effective treatment choice can be very challenging. If getting a second opinion through your treating doctor is not possible, you can get a referral from any doctor, including your general

practitioner. To help Australian patients find a NET Specialist, Neuroendocrine Cancer Australia has developed a register of NET specialists and NET MDTs to which patients can be referred (www.neuroendocrine.org.au).

Third chapter: Transition

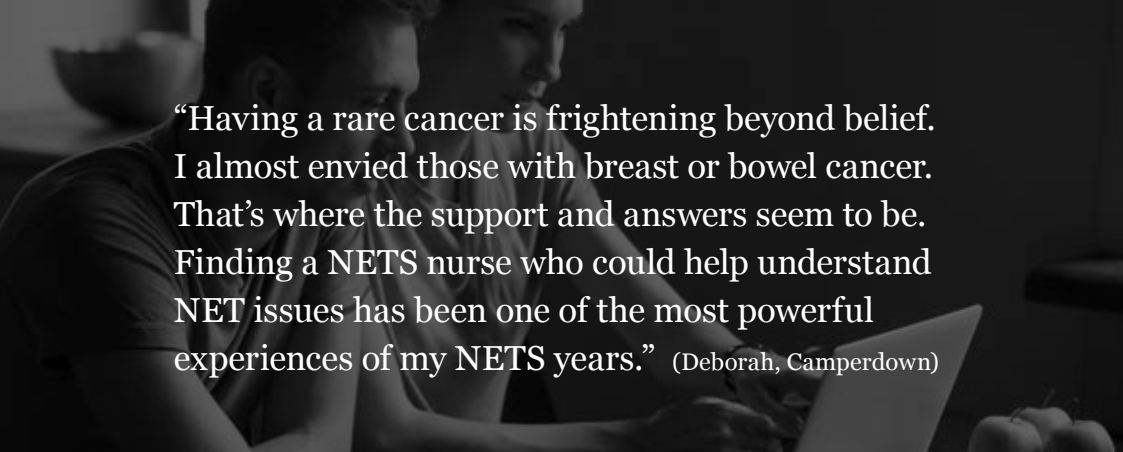
During this time, many patients are commenced on treatments and/or receive surgery for their NET.

This can be an extremely difficult and stressful period of adjustment. You may face untold emotional and physical challenges in ‘coming to grips’ with your situation and this can be compounded and magnified by the reactions of loved ones, family and friends, who are trying to help but may not understand the cancer.

You can get support and comfort during this time from Neuroendocrine Cancer Australia whose services includes NET nurse support, telephone support service and a private Facebook community where many patients converse in a safe, supportive and non-threatening forum. Other services, such as the Cancer Council helplines, can give general advice and support which includes legal and financial assistance.

“I have used the service that the NET nurse provides on many occasions. Just recently I had my first treatment of Lutate and she was very helpful to me during this time explaining that my reaction to it was a good sign. Explaining that it was a sign that the tumours had been hit hard by the treatment”

(Dorothy, Sydney)



“Having a rare cancer is frightening beyond belief. I almost envied those with breast or bowel cancer. That’s where the support and answers seem to be. Finding a NETS nurse who could help understand NET issues has been one of the most powerful experiences of my NETS years.” (Deborah, Camperdown)

Fourth chapter: Living with a NET

This is the adjustment period, when, perhaps years of misdiagnosis and the shock of being told you have a cancer, you receive expert treatment and advice and begin to comprehend the notion of ‘living with a NET’.

Living with a NET is challenging and can have a considerable impact on activities of daily life, and many NET patients need to make significant adjustments. There are so many things to think about that it can be overwhelming.

Questions about what will happen ‘next’ are at the forefront of every patient’s thoughts and actions and for many people the impact on their physical, mental and emotional health is significant.

Generally, most people with NETs describe themselves as having ‘good health’ but that often hides the reality of symptoms of fatigue, muscle weakness, intermittent abdominal pain, diarrhoea, skin rashes, headaches, anxiety and depression. It is important for caregivers, family, friends and work associates to understand that although the NET patient appears well, they are struggling with many of these symptoms and need to be supported during such times.

It is important for you to develop a ‘working’ relationship with your NET specialist, allowing them to guide your treatment.

Many NET patients describe feeling that their identity has been ‘stolen’ and replaced by an overwhelming focus on their disease. Therefore, it is vital to develop trust in your NET specialist and allow them to share this burden, which will free up time for you to pursue things in life that empower and give joy, such as family, hobbies and holidays.

Seeing your NET specialist

NET patients see their NET specialist and many other members of the NET team, including their general practitioner, on a regular basis. These appointments can be stressful as there are often many issues to discuss, questions to ask, and explanations to be given within a limited time in the consultation room or outpatient clinic.

It is vital to prepare for these consultations in order to get the most out of the time spent with your doctor.

- Take all recent pathology (blood tests) and radiology results to the appointment if you have them.
- Before the consultation, write down questions that you want to ask. If you do not understand the answers, don't be embarrassed to ask for the answer to be repeated or rephrased.
- Regularly take notes and keep in a diary of all your symptoms to take to your appointment, how you are feeling even if they seem minor or unrelated to your NET, including triggers for the symptoms, their frequency and severity, and factors that may relieve the symptoms. Some doctors are very happy for patients to email these notes through, ahead of the appointment, so they are aware of what needs to be covered. **Neuroendocrine Cancer Australia website has a Treatment and Wellness Plan which can be downloaded to assist in keeping a comprehensive record of the type of NET, tests, treatments, management and care.**
- Take a trusted friend or family member with you to the appointment. If you are feeling anxious, you may not hear everything that is 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 raised.
- Many doctors are happy for people to record their consultation on a smart phone or electronic voice recorder. This can enable you to listen back later, and provide to carers who may not be able to attend. Check with your doctor beforehand.

Deciding on a treatment strategy can be difficult, so getting a second opinion is quite common. You have the right to know as much about your condition and 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 are not successful in stabilising your disease.

You have the right to make decisions for yourself, even if the decision is against having medical treatment or is to end medical treatment.

Questions to ask during the consultation

General:

- What type of NET do I have?
- Where is the NET located? Has it spread to other parts of my body?
- What are the risk factors for NETs?
- Is my NET likely to be caused by genetic factors? Are any other members of my family at risk of developing a NET?
- Are you a NET specialist? How many NET patients do you treat a year?
- Are you able to consult with or refer me to a NET specialist?
- Are you involved with or have access to a NET multidisciplinary team?
- Where can I find out more information about my NET?
- How could it have spread when the margins were clear from surgery?

Tests

- What type of histology is my NET (the description of the NET as it looks under the microscope)? Did an experienced NET Pathologist review the tumour?
- What other tests do I need to have? (Refer to the diagnosis section. Tests may include blood tests such as chromogranin A (CgA); 24-hour urine tests (5-HIAA); functional nuclear medicine scans (Gallium-68 PET scan, FDG scan,); triple phase CT of the liver; MRI; and echocardiography of the heart.

Staging

- What is the grade and staging of my NET? What does this mean?
- Based on my grade and staging, what is my prognosis?

Management

- What are my management options?
- What is the expected timeline for my management plan? Do I need to be treated immediately?
- Which treatments, or combination of treatments, do you recommend? Why?
- What is the goal of the treatment you are recommending?
- Can I have long overseas holidays whilst on treatment?

Treatments

- What will be done during the treatment and how will it affect me?
- How often do I need this treatment? (Treatment schedule)
- Is there a home support program for this treatment, so I can have this at (or closer to) home?

- Will I need to be hospitalised for a treatment, or is this treatment done as an outpatient?
- What are the side effects or risks (short term and long term) of this treatment?
- How can I best prepare myself for this treatment?
- What should I avoid or not do while having this treatment?
- How will this treatment affect my daily life? Will I be able to work, exercise and do my usual activities?
- Does this treatment treat my symptoms of NET?
- What are the costs for my NET treatments? Are my treatments covered by Medicare, Pharmaceutical Benefits scheme (PBS) or my insurance?

Clinical trials

- What are clinical trials?
- Are there any relevant clinical trials for my NET?
- What are the benefits and risks of participating in a clinical trial?
- How will I be monitored while participating in a clinical trial?
- What are my responsibilities during a clinical trial?
- Are there any costs associated with being in the clinical trial?
- Where can I learn more about clinical trials for NET?

Support

- What supports are available to me? To my family?
- Who should I call with questions or concerns out of hours?
- May I contact you or the nurse to talk about additional information I find?
- Do you know of any support groups or resources for NET patients?
- I am concerned about managing the costs related to my NET care: who can help me with these concerns?
- Am I eligible for any benefits if I cannot work?

Patient support

Neuroendocrine Cancer Australia operates face-to-face NET support group meetings in most Australian capital cities six times per year. NET patients and carers can also access a 'closed' forum on Facebook as well as obtain information and support with our specialist NET nurse on **1300 287 363** or netnurse@neuroendocrine.org.au

It is very important for all Australian NET patients to contact Neuroendocrine Cancer Australia (neuroendocrine.org.au) or join the mailing list to remain updated on current issues related to NET in Australia.

Clinical trials

You can find out more about current NET trials at:

- Australian and New Zealand Clinical Trials Registry www.anzctr.org.au
- Cancer Australia www.australiancancertrials.gov.au
- Australian National Health and Medical Research Council www.australianclinicaltrials.gov.au
- United States National Health Institutes Clinical Trials (includes international and Australian trials) www.clinicaltrials.gov
- Current Australian NET Clinical Trials - www.neuroendocrine.org.au

Complementary (alternative) therapies

Complementary therapies are also known as natural or traditional therapies and can be divided into three main categories:

- ‘natural’ therapies: herbal and naturopathic compounds, Chinese medicines, homeopathy, etc.
- mind-body (mindfulness) techniques: meditation, relaxation, support groups, counselling, music or art therapy, hypnotherapy, aromatherapy, etc.
- physical therapies: massage, yoga, tai chi, acupuncture, reflexology, Pilates, Alexander technique, etc.

It should be noted that such therapies are not subject to the same strict regulations as evidence based therapies. Studies have shown that more than 50% of patients with cancer have used some form of complementary therapies in addition to their conventional medical treatments. For many NET patients, taking a ‘holistic’ approach to their health improves their quality of life by addressing their dietary, physical, emotional and spiritual needs.

Before starting any complementary medicines or therapies it is important to understand:

- How the therapy works.
- Will the therapy cause harm, have side effects or interact with other medications or tests?

There is no conclusive scientific evidence for that natural therapies can successfully treat cancers; however, there is anecdotal evidence for mind-body techniques and physical therapies to assist in improving pain management, sleep, stress relief, depression, anxiety and general quality of life.

It is vitally important to tell your NET specialist about any ‘natural’ medicines or complementary therapies you are using or intend to use. They can potentially have a negative impact on the disease or interact with other NET treatments and diagnostic tests.

Diet

Why diet is important

There are a number of reasons why focusing on diet and healthy eating is important for NETs patients.

Eating well can:

- Help you cope better with treatment
- Assist in healing. This is important after surgery, chemotherapy, radiotherapy or other medical treatment
- Improve your body’s immune system, its natural defense
- Help you maintain your weight and feel better in yourself. This is important even if you are not having treatment.

For those who are not losing weight, have symptoms controlled well and are otherwise well on no other prescribed diet, their focus should be to follow a healthy eating diet. This should be high in foods such as fruit, vegetables and wholegrains but low in nutrients such as salt, saturated fat and added sugar. Choose from a range of natural colours; at least three vegetable and two fruit portions a day.

Some NETs patients may need to seek advice about the right foods. Patients with pancreatic NETs in particular may have more complex needs and should seek guidance from an experienced nutritionist. See the Neuroendocrine Cancer Australia website for our [Nutrition Booklet](#).

Carcinoid trigger foods

For some patients certain foods and drinks can trigger symptoms such as abdominal pain, diarrhea and flushing. The types of foods/drinks that cause this reaction vary. The most reliable method of identifying them is with a food and symptom diary. The diary is completed over a 2-4 week period and includes foods eaten, medications and any symptoms experienced afterwards. If you identify a ‘trigger food’, try reducing the portion size. If this does not help, you may need to

exclude it completely from your diet. Possible common triggers include:

- Size of meal
- Fat content
- Spice and alcohol
- Meals moderate to high in amines (e.g. aged cheese, smoked/salted fish & meat)

Common issues and strategies

Weight loss

It is important not to ignore loss of weight. Progressive loss of weight may be as a result of a number of problems, so you should discuss this with your doctor, nurse specialist and dietitian.

General tips to boost your intake:

- Eat “little and often”
- Small frequent meals and snacks may be easier for you to manage rather than the traditional three meals per day
- Have snacks in between your meals
- Eat when you feel hungry
- Use convenience foods (ready meals, canned foods, frozen foods) if you are too tired to prepare meals.

Tips to increase your protein and energy intake:

- Eat foods rich in protein, meat, poultry, fish, eggs, dairy products (milk, yoghurt, cheese) pulses and nuts
- Have foods rich in energy, oils, nuts, butter, margarine, and any other foods high in fat and sugar. Use full-fat dairy products (e.g. whole milk, full fat cheese, full cream yoghurt, double cream)
- Have fortified milk: add 3 -4 tablespoons of skimmed milk powder to 1 pint of milk. Use in the same way that you would ordinary milk
- When having breakfast: use fortified milk or neutral flavoured supplement drinks. Try adding dried fruit, nuts, sugar, honey, yoghurt, evaporated milk or cream
- Stews or casseroles; add noodles, lentils or beans. Stir in cream or sour cream
- Soups or sauces; make with fortified milk or add grated cheese, double cream, butter or oil
- Desserts; add ice cream, cream, evaporated milk, condensed milk, jam, honey, golden syrup, lemon curd, dried fruit, nuts or chocolate

- Use fortified milk to make milky desserts (e.g. custard)
- Sandwiches, toast, plain biscuits or jacket potatoes; add butter, margarine, mayonnaise, cheese, peanut butter, olives or avocado
- Vegetable; add grated cheese, oil, butter or margarine
- Salads; use oil, mayonnaise, salad cream, salad dressing, Greek yoghurt, nuts or seeds
- Try using fortified milk in hot chocolate, smoothies or other high energy drinks
- If necessary, your dietitian may advise you to get a prescription of supplement drinks

“Regular exercise such as walking has been shown to reduce muscle wasting and fatigue, as well as nausea and vomiting, and can help some people sleep better”

(NET Specialist)

Diarrhoea

Diarrhoea may be a result of many things in NETs including the tumour-secreting hormones, treatment, intolerance to food or an infection. Here are some things to try;

- If you have diarrhoea and you have not started a new treatment, see your doctor as you may have an infection
- Eat little and often
- Reduce insoluble fibre (e.g. bran, wheat germ) but increase soluble fibre in diet (oats, apricots, high fruit jams)
- Cook and peel fruit and vegetables
- Juice ‘without bits’ rather than whole products / smoothies
- Non-dairy, multi-strain probiotics (check with your doctor if you are on chemotherapy)

Wind and bloating

This problem can accompany diarrhoea and constipation. Here are some tips to help;

- Avoid gas-forming foods (e.g. onions, garlic, cabbage, pulses, cauliflower broccoli, nuts and spicy foods)
- Trial a low fibre diet

- Avoid fizzy drinks and chewing / bubble gum
- Skipping meals is more likely to cause wind, therefore eat regular meals
- Chew your food well to reduce the amount of air swallowed
- Monitor bowel movements and speak to your doctor or nurse if the problem persists

How do I know if I am not absorbing fat appropriately?

If you have diarrhoea and/or your stools appear pale, oily, float or are hard to flush, then this might indicate that you are not absorbing fat as you should. Talk to your doctor, nurse or dietitian if your stools appear different or if you have diarrhoea. If your doctor or dietitian thinks you may have problems absorbing fat, they may recommend you take pancreatic enzyme tablets to help with this. Creon is a common brand of pancreatic enzymes and is taken at the beginning of meal times. – refer to the Vitamin / Dietary Fact Sheet on the Neuroendocrine Cancer Australia website.

Nausea and vomiting

You may feel nauseous or vomit for several reasons. Please tell your treatment team so they can investigate possible causes.

- Eat small, frequent meals throughout the day to avoid feeling full
- Take little sips of nutritious drinks between meals rather than with them
- Avoid cooking smells if possible
- Cold food and drinks usually have less smell than hot cooked foods
- Seek out tart flavours (e.g. citrus juices, sorbets and lemon curd) and salty and minty flavours
- Eat plain biscuits, crackers or dry toast
- Avoid greasy or fatty foods
- Try ginger extract in foods or drinks (e.g. crystalised stem and fresh ginger in stir fries / juices / grated onto salads)

When to ask for help

It is important to note that this is only a basic guide. It is important to discuss your needs with your treatment team, particularly if you have weight loss, diarrhoea or any other prolonged symptoms.

Financial Advice & Assistance

Support and information directory

A wide range of organisations and health professionals can help you manage the financial impact of cancer.

Financial help

- Financial Counselling Australia Information about financial counselling and help to find a counsellor. - **1800 007 007**
- financialcounsellingaustralia.org.au or debtselphelp.org.au
- MoneySmart Free financial tips and safety checks from the Australian Securities and Investments Commission (ASIC).
- **1300 300 630** - moneysmart.gov.au
- Financial Information Service (FIS) Free, confidential service from the Department of Human Services to help with investment and financial decisions. - **132 300** (say 'Financial Information Service')
- humanservices.gov.au (type 'FIS' in the search box)
- Financial Planning Association of Australia (FPA) Information about financial planning and help to find a financial planner. - **1300 626 393** - fpa.com.au
- Cancer Council Pro Bono Program Program that can connect you with a financial planner or accountant; free assistance for eligible clients. - **13 11 20**

Government benefits

- Department of Human Services Includes Centrelink and Medicare; financial support for people in need. - **132 717** (Centrelink) - **132 011** (Medicare) - humanservices.gov.au
- Pharmaceutical Benefits Scheme (PBS) Help with cost of prescription medicines. - **1800 020 613** - pbs.gov.au

Bankruptcy

- Australian Financial Security Authority (AFSA) Information about bankruptcy and personal insolvency agreements. - **1300 364 785** - afsa.gov.au
- Dispute resolution Financial Ombudsman Service (FOS) Free, independent service for resolving disputes with financial services. - **1800 367 287** - fos.org.au
- Credit and Investments Ombudsman (CIO) Free, independent service for resolving disputes with financial services. - **1800 138 422** - cio.org.au

- Telecommunications Industry Ombudsman (TIO) National independent dispute resolution scheme for complaints about phone or internet services. - [1800 062 058](tel:1800062058) - tio.com.au

Legal advice

- National Association of Community Legal Centres (NACLC) The peak national body for Australia's community legal centres, which provide free legal services. - [02 9264 9595](tel:0292649595) - naclc.org.au
- Cancer Council Pro Bono Program Program that can connect you with a lawyer if you need legal advice; free assistance for eligible clients. - [13 11 20](tel:131120)
- No Interest Loan Schemes NILS - Good Shepherd Microfinance Information about NILS providers. - [13 NILS \(13 64 57\)](tel:13136457) - nils.com.au

Taxation Australian

- Taxation Office Tax information. - [13 28 65](tel:132865) - ato.gov.au

Psychological Tips

Addressing your psychological well-being can help you feel more relaxed and in control, cope better during treatment, overcome anxiety and depression, and enjoy life.

Tips to help you improve your psychological well-being:

- Focus on what you can change, not on what you can't change.
- Cancer means something different to each individual. Everyone experiences cancer differently. so remember your experience is unique to you.
- Talk about your feelings. Reach out to family and friends, other cancer patients
- Make healthy lifestyle choices. Pay attention to your needs for rest, nutrition, exercise and private time.
- Seek professional counselling, including individual, couple, family and/or group therapy and support groups.
- Try mind-body techniques, such as relaxation therapies, laughter therapy, stress management interventions

The Cancer Council have a comprehensive library of patient information booklets which address psychological matters, including assistance for carers in caring for someone with cancer. Refer www.cancer.org.au

Travel Assistance

Patients attending consults and / or receiving treatment away from home are entitled to some financial assistance. There is a website at:

<https://www.medistays.com.au> which provides information on registering and applying for travel and accommodation assistance.

Even when you are receiving treatment, you are able to travel nationally and internationally. Travel insurance can be obtained; here are some websites which can assist you-

<https://fastcover.com.au/travel-insurance/can-you-get-travel-insurance-if-you-have-cancer#NewsLetter>

<https://www.allcleartravel.com.au/travel-insurance/cancer/>

<https://www.tga.gov.au/travelling-medicines-and-medical-devices>

<https://www.humanservices.gov.au/individuals/services/medicare/travelling-overseas-pbs-medicine>

Resources

Websites

www.netpatientfoundation.org.au

www.neuroendocrine.org.au

www.incalliance.org

www.prostate.org.au

www.cancer.org.au

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About Neuroendocrine Cancer Australia

Neuroendocrine Cancer Australia was formed in 2009 by Simone Leyden (CEO and co-founder) and Dr John Leyden (Chair and co-founder) due to the experience they had with their sister Kate's diagnosis with pancreatic neuroendocrine cancer. NeCA is an independent medical not-for-profit charity directed towards improving the outcomes of patients with NETs.

The mission of Neuroendocrine Cancer Australia is:

- to assist and support patients and carers, through support groups and access to networks of expertise
- to lobby for access to new and appropriate investigations and treatments
- to raise awareness and knowledge of neuroendocrine cancers within the medical community and general public
- to encourage and support Australian based research in the area of neuroendocrine cancers.

If you would like to know more about Neuroendocrine Cancer Australia or get involved please visit our website www.neuroendocrine.org.au or email info@neuroendocrine.org.au. All donations are most welcomed as we continue our work to improve the outcomes of NET patients.





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Cancer** Australia