Treatment & Wellness Care Plan
for people with neuroendocrine cancer

NeuroEndocrine Cancer Australia

This Treatment and Wellness Care Plan summarises information about your diagnosis, treatment, follow up care, symptoms to watch for, and steps you can take to stay healthy.

Australian Cancer Survivorship Centre
A Richard Pratt Legacy

Keep this care plan: if you see other doctors and other health care providers in the future, it will tell them about your neuroendocrine tumour, its treatment, and how best to monitor your health.

Your health care professionals will discuss healthy living recommendations that apply to you and ways in which you can achieve these. We recommend that you involve your GP in your health care plan.

Date Care Plan prepared

1. General information

Name			
Date of Birth		**Gender**	☐ Female ☐ Male ☐ Non-binary
Treatment Centre			
Hospital Record Number		**Hospital Telephone Number**	
Specialist Doctor		**contact**	
Specialist Doctor		**contact**	
Specialist Doctor		**contact**	
Specialist Nurse		**contact**	
GP		**contact**	

2. Diagnosis

Diagnosis (Primary if known)	
Date of Diagnosis (if known)	
Location of current tumor/s (if known)	
Grade (tick one)	☐ Grade 1 Mitotic index <2, Ki-67 0-2 ☐ Grade 2 Mitotic index 2-10 Ki-67 3-20 ☐ Grade 3 Mitotic index >10 Ki-67 >20 ☐ Don't know
Ki-67 Index	Date of pathology report:
Ki-67 Index biopsy	Ki-67 has changed from previous biopsy: ☐ Yes ☐ No ☐ N/A
I have had genetic testing	☐ Yes ☐ No ☐ Don't know
Mutation found	

2. Diagnosis

Classification ☐ Functioning ☐ Non-functioning ☐ Unknown

3. Record of investigations (e.g. gastroscopy, colonoscopy)

Date (if known)	**Investigation**	**Location/ site**	**Date** (if known)	**Investigation**	**Location/ site**

4. Treatment summary (in this section you can record the treatment you have received)

Surgery

Surgeon		**Hospital**	
Date (if known)		**Procedure**	
Surgeon		**Hospital**	
Date (if known)		**Procedure**	

Somatostatin Analogues (SSAs)

Specialist		**Treatment start date**	
Agents	☐ Long Acting Octreotide	**Treatment end date**	
	☐ Long Acting Lanreotide	**Dose**	
	☐ Short Acting Octreotide	**Frequency**	

Peptide Receptor Radionuclide Therapy (PRRT)

Specialist			
Date (if known)		**Agents** (e.g. Lutate)	
Date (if known)		**Agents**	
Date (if known)		**Agents**	
Date (if known)		**Agents**	
Date (if known)		**Agents**	
Date (if known)		**Agents**	

4. Treatment summary (continued)

Chemotherapy treatment/s

Specialist

Agents

☐ Temozolomide
☐ Carboplatin / Etoposide
☐ Capecitabine
☐ FOLFOX
☐ Other

Treatment start date

Treatment end date

Frequency

Liver-directed therapies

Specialist

Therapy

☐ Trans-arterial chemoembolization (TACE)
☐ Intra-arterial administration of SIR spheres (Sirtex / Y-90)
☐ Hepatic Artery Embolization (HAE)
☐ Radiofrequency Ablation

Treatment date

Treatment date

Treatment date

Treatment date

Targeted therapy

Specialist

Agents

☐ Everolimus
☐ Sunitinib

Treatment start date

Treatment end date

Frequency

Clinical trials

Study Contact		**Study Contact**	
Name of study		**Name of study**	
Start date		**Start date**	
End date		**End date**	

Watchful waiting / Active surveillance (for NET patients who are having close monitoring but no active treatment)

☐ Blood tests	**Frequency**	
☐ Urine tests (e.g 5HIAA)	**Frequency**	
☐ Serotonin and other products	**Frequency**	
☐ An echocardiogram to assess heart function	**Frequency**	
☐ Imaging studies such as PET, CT or MRI	**Frequency**	
☐ Other tests or scans (will depend on your health)	**Frequency**	

4. Treatment summary (continued)

Immunotherapy

Treatment start date

End date

Agent

Radiotherapy

Specialist

Treatment start date

End date

Frequency

List of scans you've had

Date (if known)	**Location**	**Date** (if known)	**Location**
CT Scan			
Ga-68			
FDG PET			
MRI			
Echocardiogram			

Special instructions to follow after surgery/treatment

Special instructions will vary according to type of surgery you have had, your specialist doctor's instructions and your particular needs. Other tests and scans may be prescribed depending on your particular after treatment plan. Please check with your treatment team about what is suggested for you. **You can use this section to keep a record.**

Surgery/Treatment	**Instruction**

5. Symptoms experienced and suggested management

You can use this section to keep a record of what has happened to you, medications (if any) prescribed and special instructions to follow. At times effects of treatment need to be managed by specialist services such as pain and palliative care. These services are available at any stage. **Early referral can help in getting complex symptoms under control.**

Symptoms of NETS, or side effects of NETS treatment	Suggested management
Fatigue	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
G.I. disturbance ☐ Nausea ☐ Vomiting ☐ Weight loss ☐ Flatulence ☐ Cramps ☐ Diarrhoea ☐ Steatorrhoea (pale floating fatty stool)	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Reaction at injection site	
Altered Mood ☐ Anxiety ☐ Depression	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Confusion, altered memory (chemo brain / chemo fog)	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Sleep disturbance	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Skin ☐ Rash ☐ Facial flushing ☐ Excessive sweating	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Heart problems ☐ Altered heart function ☐ Palpitations (feeling fluttering, pounding or fast heartbeats) ☐ Carcinoid Heart Disease	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Cholelithiasis (gall stones)	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Dizziness	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Headache	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Infection	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going

5. Symptoms experienced and suggested management (continued)

Symptoms of NETS, or side effects of NETS treatment	Suggested management
Mouth ☐ Dry mouth ☐ Ulcers ☐ Thrush	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Endocrine dysfunction ☐ Hypothyroidism (Reduced function) ☐ Hyperthyroidism (Increased function) ☐ Hypoglycaemia (Low blood sugar) ☐ Hyperglycaemia (High blood sugar)	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Neutropenia (low levels of part of the white blood cells that leads to increased risk of infection)	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Thrombocytopenia (low levels of clotting factors in blood that leads to increased bleeding time or easy bruising)	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Altered Liver function	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Altered Kidney function	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Reduced libido (sex drive)	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Fertility preserving options ☐ Sperm banking ☐ Egg harvesting ☐ Ovarian tissue freezing	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Breathing ☐ Bronchospasms ☐ Cough ☐ Wheezing ☐ Dyspnoea (difficulty with breathing, short of breath)	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Hypertension (high blood pressure)	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Alopecia (hair loss)	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Metalic taste	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going

5. Symptoms experienced and suggested management (continued)

Symptoms of NETS, or side effects of NETS treatment	Suggested management
Peripheral neuropathy (Weakness, numbness and pain from nerve damage) ☐ Hands ☐ Feet	**Symptoms occurred** ☐ Before diagnosis ☐ Post treatment ☐ On going
Others	

Future treatments (if known)

Contacting a health professional about signs and symptoms

Some symptoms you experience may be normal. However, if you have symptoms that are not settling and are concerning you such as heart palpitations, skin rashes, excessive bowel motions, speak with your treatment team, your specialist nurse at your treating hospital or your GP. Also report any new symptoms that, persist for more than a week, or are unexplained. Some symptoms may not be related to your NET or treatment, but it is important to have them checked out.

6. Referral to Supportive Care services and Allied Health

If you have received referral to some of the services listed below, you may wish to record contact details.

Service	Main reason	Provider name and contact	Referral Sent
Continence Support			☐
Dental			☐
Diabetes Educator			☐
Dietician			☐
Fertility			☐
Genetic Counselling			☐
Menopause Counselling			☐

Appointments booked	

6. Referral to Supportive Care services and Allied Health (continued)

Service	Main reason	Provider name and contact	Referral Sent
Occupational Therapy			☐
Pain and Palliative Care			☐
Physical Therapy			☐
Psychiatry			☐
Psychology			☐
Sexual Counselling			☐
Social Work			☐
			☐
Appointments booked			

Labs

I have had the following labs and possess the report (if applicable). Indicate if abnormal.

Type of lab	Date(s)	Report
☐ Complete Blood Count (CBC)		☐
☐ Electrolytes		☐
☐ Chromagranin A (CgA)		☐
☐ Serotonin		☐
5-HIAA ☐ urine ☐ plasma		☐
☐ Plasma (Blood)Metanephrine and/or 24hr urine)		☐
☐ Neurokinin A		☐
☐ HbA1c		☐
☐ Other		☐
☐ Other		☐
☐ Other		☐
☐ Other		☐

Additional information

Diabetes	☐ Pre Diabetes ☐ Type 1 ☐ Type 2 ☐ Other
Notes on Diabetes e.g. diet controlled, glucose lowering medication or insulin	

6. Referral to Supportive Care services and Allied Health (continued)

Additional information

Allergies	
Family history	
Medications / supplements	

Follow-up plan

Your follow-up plan will depend on your particular circumstances and treatments you have received. Your health care team will advise you. Ask them to provide you with details about your next appointments and scans.

At a typical follow-up appointment you may expect some of the following:

- History (talking about your health) and examination
- Blood tests / urine tests for biochemical markers (for example serotonin and other products) may be checked regularly
- An echocardiogram to assess heart function usually every 6 months
- Imaging studies such as PET, CT or MRI may be done every 6-12 months
- Other tests or scans will depend on your health

7. Making a plan to live well

Having cancer often makes people think about their health in different ways. Some people decide they want to live a healthier lifestyle than they did before getting cancer. Some people look for ways to reduce the chance of the cancer coming back and prevent a new cancer.

Research shows that one in three cancers in Australia are due to modifiable lifestyle factors such as smoking, UV radiation, poor diet, overweight and obesity, alcohol and not enough physical activity.

This may be a good time to make some changes and commit to staying healthy. Simple measures may help to prevent developing another cancer. They may also reduce many of the physical and emotional effects of cancer treatment.

Free health and wellness programs are held by cancer councils in all states. Joining these types of programs can help you make healthy lifestyle changes, They can also help you become active and eat better. Visit the cancer council wesbite to a find a program to suit your needs.

www.cancer.org.au

Visit Neuroendocrine Cancer Australia website for general healthy living recommendations for people who have had treatment or are having treatment for a NET. They have links to webinars (about diet; exercise; anaesthetics and NETs) and links to other helpful resources that provide further information.

www.neuroendocrine.org.au

Making regular appointments with your GP

There are a lot of things you can do to improve your health when you have been diagnosed with a NET. A key thing you can do is have a regular GP. Your GP is the cornerstone of your healthcare. During your cancer treatment, you can make sure your GP is kept informed about your hospital care. During and after cancer treatments, your GP can help with all your different health needs, including some of your cancer-related health needs.

If you do not have a GP, try to find one you can develop a trusting relationship with, who can meet your needs. Let your specialist know who your GP is; that way, communication can flow between your specialist, the hospital where you are treated, and your GP.

Some people benefit from having a formal management plan that outlines all aspect of your after cancer-treatment care. Your GP may suggest developing a management plan to provide an organised approach to your care. If your care requires treatment from two or more other health care providers, your GP may suggest a team care arrangement plan to coordinate your care. General practice nurses work in GP surgeries as part of your healthcare team. They are also available to help you manage any long term medical conditions and to support you in making healthy lifestyle changes. The Australian Cancer Survivorship Centre – A Richard Pratt Legacy (ACSC) has produced a fact sheet.

www.petermac.org/cancersurvivorship

ACSC has also produced a video for survivors, family and friends explaining the role of the GP: Watch this video to learn how hospital staff and general practice can share care to benefit cancer survivors. Specialists describe how clear roles and care plans can support shared care, GPs describe how shared care has improved care for patients, and a survivor describes her experience of shared care.

www.youtube.com/watch?v=6mzU4-dwNU0&feature=youtu.be

Neuroendocrine Cancer Australia can provide you with a Health Care Professional booklet about NETs to help explain your disease to your GP.

www.neuroendocrine.org.au

Maintaining healthy weight

Research shows that a waistline over 100cm for men and 85cm for women significantly increases the risk of some cancers.

www.cancervic.org.au/preventing-cancer/weight

Obesity can worsen the side effects of cancer treatment and cause illness. Obesity increases the risk of developing another cancer. Achieving and maintaining a healthy weight is linked to physical activity and eating a healthy diet. For more information you may wish to visit the LiveLighter website. LiveLighter is a program developed in Western Australia. It aims to encourage Australian adults to lead a healthier lifestyle and support the trial, adoption and maintenance of healthy eating, physical activity and healthy weight.

www.livelighter.com.au/About/

Limit alcohol if you drink

Drinking alcohol may trigger symptoms for people who have carcinoid syndrome.

Drinking alcohol increases the risk of certain cancers. It is recommended people limit or avoid drinking alcohol. For people who do drink alcohol, no more than two standard drinks a day, avoid binge drinking and have at least 1 or 2 alcohol-free days each week. It is important to talk to your GP about alcohol consumption if you drink more than a moderate amount each week.

www.cancervic.org.au/preventing-cancer/avoid-alcohol

Healthy diet

Food and diet are an important part of our lives (emotionally, socially and for our physical health) and is something that you can have control over. Many people seek a special diet that will ‘cure’ or treat their condition. Diet is not able to cure your disease. Eat a diet that is balanced with protein and carbohydrates and is reduced in fat. Your diet needs to meet your energy needs and ensure your weight remains stable

What you eat can help reduce symptoms and side effects of treatment. To help control symptoms , some people, may be advised to cut out certain types of food by their doctor, nurse or dietitian. It is recommended to discuss this first with your treatment team.

Many people who are unwell experience poor appetite and weight loss. Weight loss can be caused by various factors and therefore should be discussed with your doctor, nurse or dietitian. A diet high in protein and energy can correct weight loss if it is a result of not eating enough.

A healthy diet is also recommended to reduce the risk of certain cancers.

Ask your treatment team about a referral to a dietitian who can carry out a detailed nutritional assessment and provide specialist advice. Links below are to other information you may find helpful.

www.cancervic.org.au/preventing-cancer/weight

www.neuroendocrine.org.au/page/8/what-are-nets

Be physically active

Physical activity and resistance exercise are important for healthy living and have been shown to have important benefits for cancer survivors. Exercising regularly helps to reduce cancer-related fatigue (see our fact sheet).

www.petermac.org/sites/default/files/ACSC_FactSheet_Fatigue%20WEB.pdf

Exercise improves your fitness and muscle strength and reduces excess fat.

Cancer Council Australia recommends exercise during and after cancer treatment to:

- reduce anxiety and fatigue
- improve self-esteem
- increase feelings of optimism
- improve heart health
- maintain a healthy weight
- boost muscle.

Exercise is important to reduce the risk of many cancers. Up to 1 hour of moderate activity daily or 30 minutes of vigorous activity is recommended.

www.cancervic.org.au/preventing-cancer/be-physically-active

www.cancervic.org.au/living-with-cancer/exercise

Be sun smart

The sun's ultraviolet (UV) radiation is a major cause of skin cancer. In Victoria UV levels generally reach 3 and above from September to April. UV levels of 3 and above can cause damage and increase your risk of skin cancer so a combination of sun protection steps are needed. Avoid sunburn by minimising sun exposure when the SunSmart UV Alert exceeds 3 and especially between the hours of 10 am and 4 pm, when UV levels reach their peak.

- Look and listen for UV Index levels in local weather forecasts.
- Use a combination of sun protection measures against UV radiation: never rely on just one.
- Seek shade; wear a hat that covers the head, neck and ears; wear sun-protective clothing and close-fitting sunglasses; and wear a SPF50+ sunscreen (i.e. 'slip, slop, slap, slide, seek').
- Do not use solariums (tanning salons). These are already banned in some states.

www.cancervic.org.au/preventing-cancer/be-sunsmart

Quit / avoid smoke

It is never too late to stop smoking. Quitting smoking is one of the best decisions you can make. It reduces the chances of some cancers returning or developing another cancer. Your GP and General Practice Nurse can support you with a plan for quitting smoking and can recommend tobacco substitutes such as patches. Your GP can prescribe other medications to help you quit as appropriate.

Call the Quitline 13 7848 . Quit specialists offer help with quitting and will give you reliable information and support. A free Quit pack can be mailed to you. For non-smokers, breathing in other people's cigarette smoke can increase your risk of cancer.

Cancer Council Australia recommends making sure that you and your family are smoke free. Tips to avoid second hand smoke include: being a smoke free model for others and making your home and car smoke free.

Smoking causes cancer. Smoke contains over 60 chemicals known to cause cancer.

www.cancervic.org.au/preventing-cancer/quit-smoking

Finding cancer early

Keep your general health up-to-date. Screening for other common cancers is important. Finding cancer early offers one of the best chances to cure the disease. Some cancers have screening programs to find cancer early. The following link provides information about screening for common cancers.

www.cancervic.org.au/preventing-cancer/attend-screening

Health maintenance

A vaccine is available for the flu. It is recommended 'at risk' people, such as those with a NET or a chronic illness have an annual flu vaccination. Flu viruses change continually. Immunity from the vaccine doesn't last a long time. It is recommended that you receive an annual influenza vaccination.

www.healthinsite.gov.au/topics/Influenza_Vaccine

Emotional impact of cancer

Fear of cancer progressing is common during and after finishing a treatment. It can help a lot to talk to people close to you about your feelings and worries. Or you may prefer to talk to your specialist nurse, treating doctor or a counsellor. It may help to join a support group or speak with another cancer survivor.

One of the main aims of Neuroendocrine Cancer Australia is to provide support to patients by bringing them together in a relaxed yet informative environment. Neuroendocrine Cancer Australia has established patient support groups in all major cities around Australia as well as online peer to peer support. Visit Neuroendocrine Cancer Australia website

www.neuroendocrine.org.au/page/128/patient-support-groups

Or contact Neuroendocrine Cancer Australia NET Nurse.
Telephone: 1300 CURE NETS (1300 287 363)
Email: netnurse@neuroendocrine.org.au

Or call the Cancer Council Information and support line on 13 11 20 and ask about Cancer Connect, a free and confidential telephone peer support service that connects someone who has cancer with a specially trained volunteer who has had a similar cancer experience.

The following links provide information on ways to look after your mental health and useful strategies to implement.

www.petermac.org/sites/default/files/ACSC_FactSheet_Fear%20of%20Cancer%20Coming%20Back_WEB.pdf

www.cancervic.org.au/living-with-cancer/learning-to-relax

www.petermac.org/sites/default/files/ACSC_FactSheet_emotional%20impact%20of%20cancer_WEB.pdf

You may prefer to talk to a doctor or a counsellor. The Australian Psychological Society (APS) Find a Psychologist™ service can help you find a psychologist to suit your needs. They provide an online search, a telephone service and an email referral service to those who are seeking the advice and assistance of a qualified and suitable APS psychologist in private practice. Referrals are drawn from their database of more than 10,000 APS registered psychologists around Australia, covering every state and territory.

www.psychology.org.au/FindaPsychologist/Default.aspx?#About

7. Making a plan to live well (continued)

Work and finances

Some people continue to work during treatment. Others may have stopped work. Cancer council have developed a booklet called 'Cancer, Work and You'. The booklet contains information about ' how cancer can affect your ability to work, tips about working during treatment, things to consider when returning to work after a break due to treatment, information for working carers, and an overview of your rights and entitlements'. To get a copy, call the cancer council information and support line 131120 or visit the website

www.cancer.org.au/about-cancer/patient-support/working-with-cancer.html

There is also a range of useful materials on the website about dealing with practical issues, financial issues, superannuation and legal rights and responsibilities.

Work after Cancer website is a resource to support work during and after cancer diagnosis, providing advice to people diagnosed with cancer, their loved ones, clinicians and employers.

www.workaftercancer.com.au

Centrelink (132717) provides information on employment disability, sickness and carers payments.

www.centrelink.gov.au

Wellness and Life after Cancer –
For those people living with a cancer diagnosis

Consider attending a Wellness and Life After Cancer forum. This free program is suitable for people who are receiving ongoing treatments for their cancer as well as those who have completed treatment. It can help you, and those around you, develop practical strategies for managing life now and assist in shifting the focus to wellness. Visit the Cancer Council Website

www.cancer.org.au

Health and wellness goals to discuss with your GP or the general practice nurse

8. Cancer-related resources for more information

Neuroendocrine Cancer Australia is the only Australian not-for-profit medical charity focused on neuroendocrine tumours (NET). The role of Neuroendocrine Cancer Australia is to provide patient and carer support through support groups, NET nurse telephone support and resources, to raise awareness about NETs within the medical community and general public, to fund and encourage unique Australian research and to lobby for new and innovative treatments and diagnostics.

In order to create your care plan please visit the website.

www.neuroendocrine.org.au

The Australian Cancer Survivorship Centre aims to improve health outcomes for cancer survivors, and provides timely and relevant information on important issues related to cancer survivorship. The time after completing cancer treatment can bring questions or anxiety. Many cancer survivors find it helpful to access information and support services in the time after treatment:

www.petermac.org/cancersurvivorship

The Cancer Council in your state provides information and support for cancer survivors. They run a free telephone based support service called Cancer Connect, where you can speak with another cancer survivor: Telephone 13 11 20 for details.

www.cancer.org.au

9. Notes and additional information

You can use this section to add extra notes or refer information that didn’t fit in earlier sections of your plan

Section	Note