

# Treatment & Wellness Care Plan for people with neuroendocrine tumours



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.

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.

Australian Cancer Survivorship Centre

A Richard Pratt Legacy



Date Care Plan prepared

## 1. General Information

Name	<input type="text"/>		
Date of Birth	<input type="text"/>	Gender	<input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> Non-binary
Treatment Centre	<input type="text"/>		
Hospital Record Number	<input type="text"/>	Hospital Telephone Number	<input type="text"/>
Specialist Doctor	<input type="text"/>	contact	<input type="text"/>
Specialist Doctor	<input type="text"/>	contact	<input type="text"/>
Specialist Doctor	<input type="text"/>	contact	<input type="text"/>
Specialist Nurse	<input type="text"/>	contact	<input type="text"/>
GP	<input type="text"/>	contact	<input type="text"/>

## 2. Diagnosis

Diagnosis (Primary if known)	<input type="text"/>		
Date of Diagnosis (if known)	<input type="text"/>		
Location of current tumor/s (if known)	<input type="text"/>		
Grade	<input type="text"/>	Ki-67 Index	<input type="text"/>
Genetic Testing	<input type="text"/>		

### 3. Record of Investigations

Date (if known)	Investigation	Date (if known)	Investigation

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

#### Surgery

Surgeon		Service	
Date (if known)		Procedure	
Surgeon		Service	
Date (if known)		Procedure	

#### Somatostatin Analogues (SSAs)

Specialist

Agents  Sandostatin® [Octreotide (short acting)]  Sandostatin LAR® [Octreotide (long acting)]

Somatuline Autogel® [Lanreotide (long acting)]  Home injection service

#### 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	<input type="text"/>		
Agents	<input type="checkbox"/> Temozolomide	<input type="checkbox"/> Other	<input type="text"/>
	<input type="checkbox"/> Carboplatin / Etoposide		
	<input type="checkbox"/> Capecitabine		

### Liver-directed therapies

Specialist	<input type="text"/>	
Therapy	<input type="checkbox"/> Trans-arterial chemoembolization (TACE)	
	<input type="checkbox"/> Intra-arterial administration of SIR spheres (Sirtex / Y-90)	

### Biological therapies

Specialist	<input type="text"/>	
Agents	<input type="checkbox"/> Everolimus	<input type="checkbox"/> Sunitinib

### Clinical Trials

Study Contact	<input type="text"/>	Study Contact	<input type="text"/>
Name of study	<input type="text"/>	Name of study	<input type="text"/>

### Watchful Waiting (for NET patients who are having close monitoring but no active treatment)

<input type="checkbox"/> Blood tests / urine tests (for biochemical markers CgA, 5HIAA, serotonin and other products)	Frequency	<input type="text"/>
<input type="checkbox"/> An echocardiogram to assess heart function	Frequency	<input type="text"/>
<input type="checkbox"/> Imaging studies such as PET, CT or MRI	Frequency	<input type="text"/>
<input type="checkbox"/> Other tests or scans (will depend on your health)	Frequency	<input type="text"/>

## 4. Treatment Summary (continued)

### 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

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	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	
G.I. disturbance <input type="checkbox"/> Nausea <input type="checkbox"/> Vomiting <input type="checkbox"/> Weight loss <input type="checkbox"/> Flatulence <input type="checkbox"/> Cramps <input type="checkbox"/> Diarrhoea <input type="checkbox"/> Steatorrhoea (pale floating fatty stool)	
Reaction at injection site	
Altered Mood <input type="checkbox"/> Anxiety <input type="checkbox"/> Depression	
Confusion, altered memory (chemo brain / chemo fog)	
Sleep disturbance	
Skin <input type="checkbox"/> Rash <input type="checkbox"/> Facial flushing <input type="checkbox"/> Excessive sweating	
Heart problems <input type="checkbox"/> Altered heart function <input type="checkbox"/> Palpitations (feeling fluttering, pounding or fast heartbeats)	
Cholelithiasis (gall stones)	
Dizziness	
Headache	
Infection	

## 5. Symptoms experienced and suggested management (continued)

Symptoms of NETS,  
or side effects of NETS treatment

Suggested management

<p><b>Mouth</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Dry mouth</li> <li><input type="checkbox"/> Ulcers</li> <li><input type="checkbox"/> Thrush</li> </ul>	
<p><b>Endocrine dysfunction</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Hypothyroidism (Reduced function)</li> <li><input type="checkbox"/> Hyperthyroidism (Increased function)</li> <li><input type="checkbox"/> Hypoglycaemia (Low blood sugar)</li> <li><input type="checkbox"/> Hyperglycaemia (High blood sugar)</li> </ul>	
<p><b>Neutropenia</b> (low levels of part of the white blood cells that leads to increased risk of infection)</p>	
<p><b>Thrombocytopenia</b> (low levels of clotting factors in blood that leads to increased bleeding time or easy bruising)</p>	
<p><b>Altered Liver function</b></p>	
<p><b>Altered Kidney function</b></p>	
<p><b>Reduced libido (sex drive)</b></p>	
<p><b>Fertility preserving options</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Sperm banking</li> <li><input type="checkbox"/> Egg harvesting</li> <li><input type="checkbox"/> Ovarian tissue freezing</li> </ul>	
<p><b>Breathing</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Bronchospasms</li> <li><input type="checkbox"/> Cough</li> <li><input type="checkbox"/> Wheezing</li> <li><input type="checkbox"/> Dyspnoea (difficulty with breathing, short of breath)</li> </ul>	
<p><b>Hypertension (high blood pressure)</b></p>	
<p><b>Alopecia (hair loss)</b></p>	
<p><b>Metalic taste</b></p>	

## 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

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
Continence Support		
Dental		
Dietician		
Fertility		
Genetic Counselling		
Menopause Counselling		
Occupational Therapy		

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

Service	Main reason	Provider name and contact
Pain and Palliative Care		
Physical Therapy		
Psychiatry		
Psychology		
Sexual Counselling		
Social Work		

### 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 website to find a program to suit your needs.

[www.cancer.org.au](http://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](http://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.



## 7. Making a plan to live well (continued)

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](http://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](http://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](http://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](http://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/](http://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](http://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](http://www.cancervic.org.au/preventing-cancer/weight)

[www.neuroendocrine.org.au/page/8/what-are-nets](http://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](http://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](http://www.cancervic.org.au/preventing-cancer/be-physically-active)

[www.cancervic.org.au/living-with-cancer/exercise](http://www.cancervic.org.au/living-with-cancer/exercise)

## 7. Making a plan to live well (continued)

### Be sun smart

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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](http://www.cancervic.org.au/preventing-cancer/be-sunsmart)

### Quit / avoid smoke

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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](http://www.cancervic.org.au/preventing-cancer/quit-smoking)

### Finding cancer early

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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](http://www.cancervic.org.au/preventing-cancer/attend-screening)

### Health maintenance

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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](http://www.healthinsite.gov.au/topics/Influenza_Vaccine)

### Emotional impact of cancer

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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](http://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](mailto: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](http://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](http://www.cancervic.org.au/living-with-cancer/learning-to-relax)

[www.petermac.org/sites/default/files/ACSC\\_FactSheet\\_emotional%20impact%20of%20cancer\\_WEB.pdf](http://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](http://www.psychology.org.au/FindaPsychologist/Default.aspx?#About)

## 7. Making a plan to live well (continued)

### Work and finances

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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](http://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](http://www.workaftercancer.com.au)

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

[www.centrelink.gov.au](http://www.centrelink.gov.au)

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

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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](http://www.cancer.org.au)

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

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## 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](http://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](http://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](http://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