

Journal

A part of your guide to
Neuroendocrine Tumours (NETs)



My journal

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Introduction

Living with a serious disease like a neuroendocrine tumour may not be easy for you at first, but there's still a lot you can do to help make each day easier and help you feel more in control.

Your medical details and treatment tracker

This document is intended to help you keep a record of important details that you may need to share with healthcare professionals throughout this journey. Take a copy with you to your various appointments and ask your healthcare professionals to help you complete it.

You can keep this book with you to have all your important details on hand, and bring along to appointments to jot down important notes or updates from your appointments.



About me

Write down your name and contact details here and the name and phone number of someone to contact in an emergency, such as a family member or a close friend.

Date



First name

Last name

Date of birth

Phone number

Email

Emergency contact: name and phone number

My healthcare team

Write down the names and contact details of the healthcare professionals in your multidisciplinary team here, such as the name of your primary care doctor and nurse, specialist NET doctor and others who are involved in your care.



General Practitioner (GP)

Name

Phone number

Clinic or hospital address

Email



Name

Phone number

Clinic or hospital address

Email



Name

Phone number

Clinic or hospital address

Email



Name

Phone number

Clinic or hospital address

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Appointments

Keep a record of any appointments that you have coming up.

Date and location	Physician	Notes

Tests

Keep a record of any tests or procedures that you may have had here. Ask a member of your healthcare team to help you complete this section and to keep it updated.

Date	Test name	Notes

Treatments

You might find it useful, or comforting, to have details of your treatment plan; a list of treatments you have had/will have, when they began/finished, any medication you are taking for NETs and when you may need a refill etc.

Treatment name

Start date

Duration

Frequency

Date of appointment

Date	Appt
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Date	Appt
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Date	Appt
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Date	Appt
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Date	Appt
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Treatment name

Start date

Duration

Frequency

Date of appointment

Date

Appt

Date

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Date

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Date

Appt

Date

Appt

Symptoms and side effects

It is always a good idea to keep track of your symptoms and any side effects you might experience, so can advise your doctor. If any symptom or side effect is particularly severe, contact your doctor immediately rather than leaving it as a note for your next visit.

Symptom or side effect

Date

Symptom or side effect**Date**

General tips for a healthy, balanced diet



Maintaining good health through nutrition is essential during treatment for NETs. It can help manage symptoms such as nausea, reduced appetite, taste changes, fatigue and gastrointestinal upsets such as wind, bloating, diarrhoea and/or constipation. It is important that you stay well-nourished and strong during your treatment by having a varied diet.



Make sure your meals include a combination of the following:

General foods to avoid for a healthy diet:

Combine:

- Protein: meat, fish, cheese, eggs and milk
- Carbohydrates: bread, pasta, rice potatoes
- Lots of fruit and vegetables

Avoid:

- Fried Foods
- Pastries, cakes and biscuits

You should also try to ensure you drink at least 8–10 glasses of liquid (not including alcohol, caffeine or soft drinks!) a day – but try to drink in between meals, rather than during, as that can fill you up too quickly and make you feel bloated.



Good liquids:

- Water
- Fruit juice (maximum of 200mls per day)
- Weak /herbal teas
- A general multivitamin and mineral may also be good if you are struggling to eat a wide variety of food but talk to your doctor to ensure this is appropriate and won't interact

with other medications. Extra vitamin D is needed in the winter months from October to April, this can be got from fortified milk, yoghurts or an additional supplement.

Quick reference diet tips

To help alleviate diarrhoea:

- Eat little and often – avoid large meals
- Eat low-fibre, starchy foods like:
 - White bread
 - White rice
 - Pasta
 - Peeled and boiled potatoes and vegetables
- Don't forget to drink and keep hydrated — smooth fruit juices (no bits!) can be a nice occasional alternative to water

Please note: If you are experiencing symptoms of malabsorption such as pale, yellow or greasy stools, large formed stool volumes or urgency in going to the toilet and/or extra wind or bloating it is very important that you inform your doctor.

Liquids to counteract dehydration (from diarrhoea):

- Apple juice mixed with mineral water
- Sports drinks
- Cup-a-soups or Bovril
- Light tea with honey or a small amount of sugar
- Clear soup (like chicken soup broth)
- Blueberry juice
- Coconut water

Food to avoid if you're experiencing diarrhoea:

- Prunes, figs, dried and acidic fresh fruit
- Insoluble fibres (brown bread)
- Seeds and nuts (particularly linseed, sesame seeds, flax seeds)
- Coffee and tea
- Alcohol
- Too fatty, fried and/or spicy



Foods to avoid when experiencing symptoms of carcinoid syndrome:

- High-fat and/or spicy foods
- Alcohol
- Foods high in substances called amines. These include:
 - Mature cheeses
 - Alcohol
 - Smoked/salted fish/meat
 - Fermented tofu
 - Miso
 - Sauerkraut
 - High-caffeine foods
 - Chocolate
 - Peanuts and Brazil nuts
 - Raspberries
 - Soy bean products like soy sauce
 - Broad beans

Please note: You should also try to avoid eating large meals. Instead try eating more meals of a smaller size.

Food and symptoms diary

In this part of your journal you can monitor the food you have eaten at different meal times and the symptoms experienced as a result. This can help you track the foods you should avoid and when they affect you most.

<u>Time of day</u>	<u>Date</u> / /	<u>Time of day</u>	<u>Date</u> / /
Meal details		Meal details	
Symptoms		Symptoms	
<u>Time of day</u>	<u>Date</u> / /	<u>Time of day</u>	<u>Date</u> / /
Meal details		Meal details	
Symptoms		Symptoms	
<u>Time of day</u>	<u>Date</u> / /	<u>Time of day</u>	<u>Date</u> / /
Meal details		Meal details	
Symptoms		Symptoms	

Time of day

Date / /

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Meal details

Symptoms

If you would like to continue monitoring your food and symptoms, why not photocopy these pages to add to your diary.

<u>Time of day</u>	<u>Date / /</u>	<u>Time of day</u>	<u>Date / /</u>
Meal details		Meal details	
Symptoms		Symptoms	
<u>Time of day</u>	<u>Date / /</u>	<u>Time of day</u>	<u>Date / /</u>
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Meal details

Symptoms



Carcinoid crisis can occur when NET patients are given anaesthetics, e.g. for surgery. This can be fatal and medical staff need to be aware of this possibility when dealing with a NET patient. In urgent or emergency circumstances, it can be beneficial for NET patients to have an identifier on their person which identifies them as a NET patient who may require octreotide infusions.

Here is a pre-worded Carcinoid Crisis Card which you should carry with you at all times.



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