



Living

A part of your guide to
Neuroendocrine Tumours (NETs)

This handbook is designed to help you with the day-to-day reality of living with NETs. It gives clear, practical advice on how to talk to family and friends about your diagnosis; how to manage your symptoms and the emotional, physical and social challenges of your diagnosis, and how to connect with others who are living with the disease.

Living with NETs

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Introduction

When you've been diagnosed with a neuroendocrine tumour (NET), it can be reassuring to know that you are not alone. Many people can survive a long time with NETs; there are more people living with NETs around the world at any given time and treatments continue to develop to enhance the quality of their lives.

Initial reactions

You may have been experiencing a range of strong emotions lately. These could include shock, anxiety, fear, anger, sadness, distress or even guilt.

Do remember that these are all natural reactions to a diagnosis of cancer or any chronic condition.

The truth is, there is no right or wrong way to feel or to cope when you are faced with a cancer diagnosis. Your feelings and reactions are your own, and you know best what works for you.

Talking to friends and family may help. Many patients report that sharing with other NETs patients through a patient network is a great way to gain more insight and understanding of the condition. The internet can help too, but remember to use it carefully and always refer to your doctor or nurse with anything you read that worries or concerns you.

In the additional resources section of this book you'll find links to places where you can find more information, as well as lists of patient networks and other resources.

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Telling family and friends

When to talk to friends and family about your diagnosis is a very personal decision. But there's no doubt that sharing your hopes, fears and medical updates with others can make things easier for you.

It can be difficult to explain everything, especially if you are feeling tired, so think about how much you want to share. You can tell people as little or as much as you feel is right. A simple explanation of what type of NETs you have, which treatments you might need and what the long-term prognosis is for your condition is enough. Sharing these handbooks with friends and family will help them get a better understanding of what you are going through and what to expect in the future.

If questions that you can't answer come up as you talk to your friends and family, it can be a good idea to take a note of them, so you can discuss them with your doctor or medical team.

In the Journal book provided in this pack, you'll also find a list of resources for friends and family of NET patients.

Social media is another good way to communicate with friends, family and fellow-patients. A private Facebook or WhatsApp group can help you keep in touch and share links to NETs information and resources. Some people find writing a regular email or blog can be very helpful because as well as sharing information with the people you care about, it also acts as a personal journal where you can express your feelings and thoughts.

Visit:
www.ga2.mylifeline.org
and follow steps to
“create your lifeline page”
to find out how to create
your own blog.

Some tips for talking to others:

- Know the key points you want to share
- Share the news only when you feel ready
- Be prepared for questions, but don't feel like you have to answer them all
- Draw boundaries. You don't have to share every detail about your diagnosis with everyone
- Ask a friend or family member to help explain your condition to other people

Help your friends and family adjust

Your friends and family may also be looking for a comfortable way to talk to you about your diagnosis and the long-term reality of living with your condition. They might need direction on how to behave around you. You can guide them by letting them know how you feel and what you need, which can help them understand your feelings and how they can help.

Sometimes, friends and family can react badly to the news of the diagnosis. They may not be able to cope or relate to what you are trying to tell them. They may be uncomfortable discussing your condition and may even choose to avoid you.

Remember, just as you may have needed some time to come to terms with things, so might they, so don't be hurt or offended by these kinds of reactions. Not everyone is comfortable talking openly about cancer, so give people some time. Meanwhile, turn to other friends and family for support. The best support is often found in the least expected places.

Talking to children

If you have children, it's important to tell them what you can, in a way that's appropriate for their age.

Children's reactions and needs will vary depending on their age. Young children can sense a change in atmosphere at home very easily.

If they pick up on the idea something is not right, but can't grasp why, it can make them feel stressed and uneasy. The best thing to do is to explain your condition and what is happening in an open, sensitive way, using language that they can understand. With very young children, you can use dolls or pictures to help.

Usually, children of any age will want to know how your diagnosis will affect them. If you will be away for medical appointments, for example, they'll be reassured to know that rather than being mysteriously absent, you're with the doctor who's helping you with your illness. So tell them what's happening and where you are.

It's about keeping them in the picture as much as you can, without alarming them.

Older children and teenagers can use the internet to find out more, but be sure to direct them to specific links, groups or pages to make sure they are getting the right information. It's important for everyone, including you, to use the internet carefully. While it's a useful source of information, not all of it is regulated or reliable, and every NET case is unique, so even accurate information may not apply. Your doctor and medical team will always be the best source for information about your diagnosis.

The additional resources section in of this book lists some useful links and resources for talking to children, family members and friends about your cancer, as well as another section, which is specifically for them.

Visit:
[cancer.ie/publications/
children-cancer](https://cancer.ie/publications/children-cancer)
and follow steps to download
the "Talking to Children
about Cancer" PDF



Lifestyle

The good news is that the vast majority of patients maintain perfectly normal lives once their symptoms are controlled. Treatments and support for NETs are improving all the time and many people lead active, healthy lives, both during and after treatment.

There are things you can do to help yourself cope better with your symptoms and any possible side effects of your treatment. Just a few, simple lifestyle changes – especially relating to diet and exercise – will help you feel better, both physically and mentally.

For lifestyle questions, you could speak to other NET patients, or to one of the therapists you'll find through the NETs Patient Network, an organisation set up to serve NETs patients in Ireland.

The following chapter deals with this subject. Contact details for this and other patient support groups are listed in the additional resources section of this book.

Each patient's dietary advice will vary according to symptoms, so ask your doctor what is right for you.

Exercise and rest

Staying healthy during and after your treatment is the best way to ensure a happy, healthy life after your diagnosis.

Many people find that even light exercise, like a walk in the fresh air, for example, helps to relieve fatigue and improve energy levels, boosting your overall health.

Rest is very important too. Getting plenty of sleep gives your body and mind time to heal and renew. Try to make sure you get that elusive 8 hours a night and take naps whenever you feel you need them. Resting well will also help keep stress at bay, which is critical to your treatment and recovery. If you are feeling tired but unable to sleep, you can still relax by resting with your feet up and your eyes closed, maybe listening to some music or an audio book. This is sometimes referred to as “quiet wakefulness”, and will help calm the mind and relax the body.





Diet

When you are ill or trying to control symptoms, a healthy, balanced diet is more important than ever. Eating the right foods can help you to:

- Reduce NETs symptoms
- Reduce your dietary restrictions
- Increase your quality of life
- Recover and heal after treatment

Each patient's dietary advice will vary according to symptoms, so ask your doctor what is right for you. However, doctors usually advise all patients to make sure they eat regular meals of moderate portion size.

The health benefits of eating well with NETs

Eating well with NETs can:

- Help you cope better with treatment
- Help with healing of wounds and damaged tissues. This is especially important after surgery, chemotherapy, radiotherapy or other medical treatment.
- Help Improve your body's immune system
- Help you maintain a healthy weight and feel better overall, even if you're not having treatment.

If you have been diagnosed with Carcinoid Syndrome

Symptoms of Carcinoid Syndrome can be aggravated by stress and anxiety. There are also dietary triggers, like drinking alcohol and caffeinated drinks or eating certain types of food.

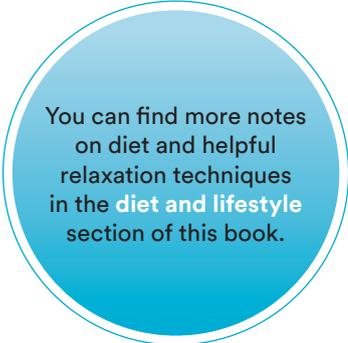
Being aware of these triggers can help you avoid or alleviate some symptoms of Carcinoid Syndrome.

Diet:

- Reduce your consumption of alcoholic and caffeinated drinks
- Avoid eating foods that contain high levels of the amino acid tryptophan (e.g. chocolate, milk and cheese, red meat, fish and poultry) or serotonin (e.g. bananas)
- Avoid high fat and spicy foods
- Avoid large meals

Stress and anxiety:

- Try to avoid stressful situations
- Practise simple relaxation techniques
- Get more exercise



You can find more notes on diet and helpful relaxation techniques in the **diet and lifestyle** section of this book.

Your work life

Work / NETs Balance – An important question you may ask after diagnosis is: “Will I be able to work?”

The answer will largely depend on your personal situation; how you feel during and after treatment, the type and stage of your tumours, as well of the type of work you do. The good news is that many people with NETs continue working without difficulty after their diagnosis.

Working can be very empowering, helping you feel in control of your condition and focusing your mind on something besides your health.

You should discuss with your doctor if and when you can continue working and how it may affect your condition. Many people who want to continue working during treatment can do so in some capacity. Some manage by adjusting their work hours, working part-time or becoming self-employed. Some also choose to take a break or depending on age or financial status, to retire.

After you talk to your doctor, you can discuss the options with your employer, because your decision to continue working will also depend on their support and flexibility.

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Managing your working time

Attending medical appointments to see your doctor and receive treatments or take tests to monitor your condition will likely be part of your normal life from now on. Some appointments may be scheduled during work hours and/or at locations far from your work. Discuss this with your employer and ask your doctor if they can try to reduce your travel time, allowing you to manage your appointments, as best you can, around your employment.

Telling your employer

You are under no obligation to share all the details of your diagnosis and treatment with your employer. However, you may need to let them know about anything that could impact your ability to work — your availability, capacity, or any symptoms or side effects, which could cause a health and safety risk for yourself or others, such as fatigue, for example.

You may need to talk with your doctor or medical team before you can provide your employer with certain details. This is because you may not have the answers until you've started treatment.

Medical appointments to see your doctor, receive treatments or take tests to monitor your condition will likely be part of your normal life from now on.

Talk to your employer and doctor to find ways to reduce your travel time for appointments.

Once you are fully informed, you may want to provide your employer with some of the following details (your doctor can help you with most of these):

- If, and how long, you will be able to continue working
- Whether you will be able to perform all of your regular duties
- If you want other people in your workplace to know
- If you need to take time off from work for treatment or recovery, and when you are likely to return to work
- If you are taking any medications that may cause side effects (such as drowsiness) which could affect your performance or safety at work
- Any adjustments to your work environment or working hours that you may need.

If you do share details with your employer it is absolutely your right to request that they don't divulge them to anyone else. You should make your employer aware of your preference.

It is also important to check your employment terms to find out what information you need to share with your employer. This can vary greatly depending on the terms and conditions of your employment contract. If you take paid personal leave because of illness, your employer may require documentary evidence (such as a medical certificate) from your doctor.

If you are unsure about your rights, you can talk to the HR department at your workplace, a Citizen's Information Office, Employment Rights Ireland, or a social worker or occupational therapist. Your local patient support group or patient charity should also be able to help.

You'll find contact details for these and additional resources in this book.



Travelling and holidays

Travelling with NETs

Depending on the tests or treatments you are undergoing, you may feel tired or weak afterwards. It can be a good idea to ask a friend or family member to drive you to your appointments.

Ask your doctor about each test or treatment so you can prepare for it properly and ask for support if needed. Even if you are driving yourself, or travelling by public transport, you might like to ask a friend or family member to join you and keep you company.

Travelling away from home/holidays

Whether for a short weekend break or a longer holiday abroad, there's no reason why you can't continue to travel after a NETs diagnosis. Most people living with NETs will tell you that it's best not to let your condition define you. As much as possible, you can continue to live life as you always did, including travelling, if that's what you like to do. A trip away can help you take the time and space you need to come to terms with your diagnosis of NETs, to recharge your batteries, or to perhaps celebrate getting a good test result or mark the end of a treatment.

Travelling with medication

If you need to take medication while you are away, ask your doctor for a letter stating why the medication has been prescribed and how often you need to take it.

This is particularly important if you are carrying a liquid or injectable medication and travelling through airports or other security, where there are limits to the amount of liquids or sharp objects you can carry.

Take details of your prescription with you in case you need to get more medication while you are away. Make sure you read the patient information leaflet(s) that come with your medication(s) to check how they need to be stored and/or transported. If your medication needs to be kept cool, check how long you'll be travelling and, particularly if you will be in a hot climate, invest in a special cooling medical bag.

Medical support abroad

A big concern for many people with cancer or other chronic illnesses is what will happen if they get sick while away from home, especially in another country.

Some insurance companies may be reluctant to offer travel insurance to people with cancer or other chronic conditions. However, it is possible to get travel insurance and it can offer the peace of mind you need to travel without worry. Check out your options before booking your travel.

If you have any questions, consult with your doctor or medical team or ask your local patient support group for advice on travelling with NETs. European residents may also be eligible to apply for a free European Health Insurance Card (EHIC), which gives extra peace of mind. This covers emergency hospital treatment within the European Union and certain other countries.

Make sure your travel plans don't clash with any important check-ups or appointments and let your doctor and medical team know where you are going and for how long.

It might be a good idea to bring your Journal book when you travel. This way, if you need to visit a doctor while you're away, you'll have details of your medical history, treatment and symptoms to hand. This is particularly useful when you need to communicate these to others, especially in a country where the doctor may not be fluent in English.

Diet and Lifestyle

Loss of appetite

How to incorporate more protein and energy into your diet without having to increase the quantity of food:

- Foods rich in protein: meat, poultry, fish, eggs, dairy products (milk, yoghurt, cheese), pulses (lentils, beans, peas) and nuts
- 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
- Fortified milk: add 3–4 tablespoons of skimmed milk powder to 1 pint of milk (use in the same way that you would use ordinary milk)
- Breakfast cereals: use fortified milk or neutral flavoured supplement drinks. Add 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
- Sandwiches, toast, plain biscuits or jacket potatoes: add butter, margarine, mayonnaise, cheese, peanut butter, olives or avocado
- Vegetables: add grated cheese, oil, butter or margarine
- Salads: use oil, mayonnaise, salad cream, salad dressing, Greek yoghurt, nuts or seeds



Additional resource on diet and nutrition from NET Patient Foundation: netpatientfoundation.org

Nourishing drinks

When you are not hungry or you are unable to eat much solid food it is often easier to drink rather than eat. The following drinks are high in nutrients. They may fill you up, so it's best to drink them between meals.

- Milky drinks, such as hot chocolate, Ovaltine and Nesquik
- Use fortified milk or whole milk and add a scoop of ice cream or whey protein powder
- Try full-fat milkshakes, yoghurt drinks, fruit smoothies
- Ask your doctor or dietician for a list of, or prescription for, supplement drinks if you are not able to manage with a fortified diet alone

If lack of appetite is due to nausea and/or vomiting, try some of the following:

- Eat small, frequent meals throughout the day to avoid feeling full
- Take little sips of nutritious drinks between meals rather than with them. Aim for 8–10 glasses per day.
- Avoid cooking smells if possible (cold food and drinks usually have less smell than hot cooked foods)
- Try ginger extract in foods or drinks e.g. crystallised stem and fresh ginger in stir-fries, juices or grated onto salads
- Tart flavours e.g. citrus juices, sorbets and lemon curd
- Salty and minty flavours
- Plain biscuits, crackers or dry toast
- Avoid greasy or fatty foods



Simple deep breathing relaxation technique to help alleviate stress and anxiety

- Make yourself comfortable; sit comfortably with your back straight and feet flat on the floor
- Loosen any clothing which might restrict your breathing
- Gently close your eyes
- Begin to breath in slowly through your nose counting steadily from 1–5, and let your breath flow deep into your belly
- Without pausing, exhale slowly through your mouth counting to the same number as your inhale
- Repeat this breathing routine steadily for 3–5 minutes

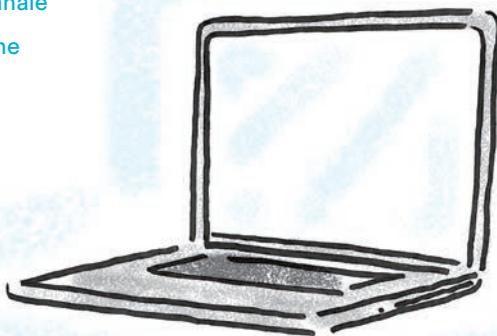
There are a number of free relaxation and mindfulness exercises available from the Mindfulness and Relaxation Centre at Beaumont Hospital visit Beaumont.ie/marc

Resources on de-stressing techniques, mindfulness and mental health

Mental Health Ireland:
mentalhealthireland.ie

Heartfulness:
heartfulness.ie

Your Mental Health:
yourmentalhealth.ie



Additional resources

NET Patient and cancer support groups in Ireland

Irish NET Patient Network:
netpatientnetwork.ie

The Irish Cancer Society:
cancer.ie

Cork Cancer Support:
corkcancersupport.ie

Purple House Cancer Support
(Wicklow):
purplehouse.ie

Irish Health:
irishhealth.com

Online and elsewhere

Net Patient Foundation:
netpatientfoundation.org

NET clinics and specialists in Ireland

netpatientnetwork.ie
and search for your nearest clinic.

Dublin

St. Vincent's University Hospital
Elm Park, Merrion Rd, Dublin 4

Phone: (01) 221 4000
stvincents.ie

Cork

Mercy University Hospital,
Grenville Place, Cork

Phone: (021) 427 1971
muh.ie

Galway

Galway University Hospital
Newcastle Rd,
Galway

Phone: (091) 524 222
saolta.ie

Information on employment security/sick leave for patients

visit: employmentrightsireland.com
and search for information on sick leave

visit: citizeninformation.ie
and search for information on rights regarding sick leave

As a carer, it is important you recognise that you may need a break too in order to regain your strength.

Resources for family and friends of NETs patients

Carers

Caring for a family member or friend with cancer can be physically and emotionally demanding. Neuroendocrine tumours can present unexpected challenges for you, as well as the person you are looking after.

Looking after your own wellbeing can help relieve stress and tiredness, as well as reduce feelings of frustration and isolation. Try to take even a short amount of time out for yourself every day.

Eat a balanced diet, get some exercise and keep up your own regular medical check-ups. Talk to your doctor about any health concerns, especially if you're feeling depressed. Recognise that you may need a break too in order to regain your strength.

Take a break

Do not feel guilty about asking for someone else to help you or for leaving the person that you are caring for in respite care for a short time.

Respite care can be given at home, in a respite care centre or, in some cases, a hospital or hospice. It can range from 2–3 hours to overnight, or even a few days.

Additional resources for family, friends and carers can be found at:
cancer.ie

Ask family for help

You may want to hold a family meeting to discuss how everyone can help. Tasks that can be done by, or shared with others include:

- Doing household chores such as cooking, cleaning, laundry, ironing or gardening
- Driving the person with NETs to appointments
- Looking up information on the internet
- Picking up children from school or their other activities
- Sitting and talking to the person you care for
- Keeping other family members updated

Here you can find plenty of information on supporting friends, loved ones and helpful tips and guidance on talking about cancer.

Ways to cope

Set boundaries about what you can manage and when you need extra help:

- Talk to charities or services that offer respite care
- Look for additional help from community nurses or local patient services
- Talk to occupational therapists about adaptations for the home
- Use a diary to keep track of information, appointments and your own concerns
- Don't expect to be perfect in looking after the person with cancer

You might also want to reach out to patient support groups for NETs. These groups can often provide social and emotional support to carers as well as patients.



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