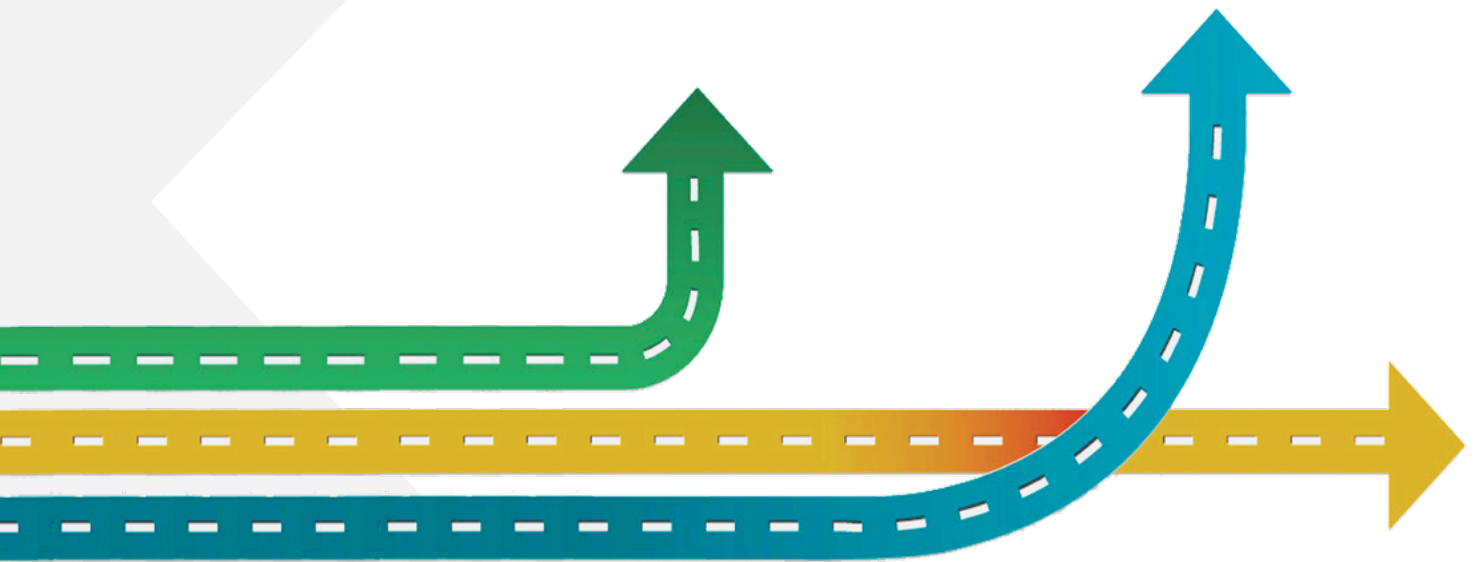


NAVIGATING THE NET PATIENT JOURNEY

Valuable Insights and Resources for Living with Neuroendocrine Cancer



OUR MISSION

To optimize the care of those with neuroendocrine cancer through the education of and collaboration among physicians, health care providers, patients, and caregivers



Dedicated to

Giovanna Joyce Imbesi, MBA

*NET Patient, Founder of Los Angeles Carcinoid
Neuroendocrine Tumor Society (LACNETS)*

We dedicate this work to Giovanna Imbesi, a tireless patient advocate who was instrumental in our vision for this project. Giovanna impacted countless patients' lives through education, advocacy and support. LACNETS created and launched NET VITALS, an important tool listed as a resource in this booklet to help patients communicate effectively with their care team.

Giovanna's creativity and compassion knew no boundaries, and as we share this NET journey with patients and families, we honor her dedication and spirit.

Introduction

As support group leaders, patients, and caregivers on this journey ourselves, we want to share what we have learned in the hope that fellow patients and caregivers can benefit from the roads we have traveled. We also invited some experts who are dedicated to the care of people with neuroendocrine cancer to share their perspective.

We hope this guide will be a useful roadmap for navigating your unique neuroendocrine journey. There are many reasons to be hopeful as there have been multiple advances in neuroendocrine cancer care in the past several years.

Wishing you strength throughout your journey. Know that you are not alone.



ADDITIONAL RESOURCES

Look for this symbol that appears throughout the guide to find additional related resources located at the back of this guide.

NOTE: We will maintain a regularly updated edition of this Resource Directory on the Healing NET website: thehealingnet.org/patient-resources



EXPERT OPINION

When you see this symbol, read the “Expert Opinion” for additional perspective.



MEDICAL INFO

When you see this symbol, note this additional medical detail.

ONLINE RESOURCE

The Healing NET Foundation has created an online hub for *Navigating the NET Patient Journey* with expanded content and resources. Visit thehealingnet.org/navigating-nets

Navigating the NET Patient Journey

is an outcome of conversation and planning over the course of several years of the International Healing NET Summit meetings. Patient advocates and support group leaders worked with physicians to examine the patient-physician relationship and ways to strengthen it in the context of NET care. This effort was supported by Ipsen Biopharmaceuticals and TerSera Therapeutics as well as by contributions from individuals. Healing NET would like to thank our funders for recognizing this need and providing the resources to meet it.

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**The opinions offered by the contributing experts do not constitute medical advice.*

You are one of a kind.

Like fingerprints and zebra stripes, no two neuroendocrine patients are exactly alike. That’s why many organizations that advocate on behalf of these patients display zebra stripes as their symbol. Another reason we use the zebra symbol is to raise awareness in the medical profession. During their medical school training, doctors are taught the old adage, “If you hear hoofbeats, think horses, not zebras,” meaning that common symptoms usually are caused by common diseases. In NETS, however, we need our doctors to be prepared to “think zebra” as well.



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1 AN UNANTICIPATED JOURNEY

There are some journeys in life that we plan for meticulously and others, like cancer, that are unexpected, immediate and scary. We refer to cancer as a journey because the diagnosis is just the beginning, the first step of many to follow. At the outset, you will likely have more questions than answers. There will be stops and starts along the way as you learn to navigate the complexities of the medical system and the twists and turns of tests and treatments. At each fork in the road, you will need to decide which course is best for you.

The Special Case of a Rare Cancer

When it comes to cancer journeys, neuroendocrine cancer is definitely one of the roads less traveled. Neuroendocrine cancer refers to all forms of this disease, both neuroendocrine tumors (NETs) and neuroendocrine carcinoma (NEC).

Most patients have never before heard of neuroendocrine cancer at the time of their diagnosis. Many primary care doctors are unaware of the signs and symptoms of this cancer. Slower-growing neuroendocrine tumors can remain “silent,” undetected and without causing noticeable symptoms, for a long time. Consequently, diagnosis is often delayed, and as many as half of all NET patients have metastatic disease at the time of their initial diagnosis. Since gastrointestinal NETs can produce symptoms similar to Crohn’s disease and irritable bowel syndrome, some patients have been treated for months, if not years, for a condition they did not have. Sometimes NETs may be mistaken for another cancer that commonly occurs in the same location, such as the lung or pancreas. But a NET in the pancreas is **not** pancreatic cancer, and a NET in the lung is **not** lung cancer. This concept can be hard to understand and a challenge to communicate to others.

Because neuroendocrine cancer is rare, it is essential that you learn as much as you can. Arming yourself with information will help you choose the best medical care team to guide you.

It is critical to understand that there is no *one size fits all* or even *one size fits most* when it comes to

WAYS TO DESCRIBE NETS

Tumors that occur in this disease all come from hormone-producing cells. There are many types of these cells making different hormones, and they are in many different parts of the body.

What we know about this disease, and the words used to describe it, continues to change over time. An older term for these tumors which is still being used is carcinoid, or cancer-like, but all tumors in this disease are now understood to be cancer. They can and do spread to other parts of the body after starting in one place. “Tumor” and “lesion” are basically the same thing: an abnormal growth of cells in your body.

NEN: Neuroendocrine Neoplasm is an umbrella term that medical professionals may use to refer to these kinds of tumors.

NET: Neuroendocrine Tumor is the term generally used to refer to the most common form of these tumors.

NEC: Neuroendocrine Carcinoma refers to a more aggressive (it spreads faster) and more harmful version of this disease.


this disease. The rule of thumb for NET patients is that **everybody is different**. Keep this in mind when you are reviewing information, seeking support and speaking to other patients.

Patient support groups, in person or online, are an excellent resource, especially for those newly diagnosed. It can be very powerful meeting others with your disease and learning about their experiences and where they seek their care. However, newly diagnosed people must be cautious because what works for one patient may not work for another. This is a complicated disease and some information will not relate to your situation. Sometimes information shared by another patient is just medically incorrect, especially online, where in most cases, there is no one to monitor or correct what is said. Additionally, while there may be commonalities of experiences or disease sites, one patient’s cancer can behave or respond very differently from another’s. The same goes for tolerating treatments and medications. Anything you consider for your medical care should be **thoroughly discussed with your trusted medical team**.

2 SETTING OFF ON THE RIGHT PATH

Prepping for the Journey

You've been diagnosed with a complicated disease, and now you're likely full of questions, beginning with *what's next?* One of the best things you can do to equip yourself for the journey is to research your disease or have a trusted friend or loved one help with this. There is no one more invested in your life than you are. Invest in yourself by learning as much as you can. Knowledge is power. It will help you understand and participate in your treatment decisions, from choosing the right provider to determining what sequence of testing and treatment is best.


The NET patient community is very fortunate that caring NET specialists and NET patient organizations have teamed up to produce a wealth of educational materials and videos that can help patients map out their journeys.  [Neuroendocrine Cancer Organizations](#)

Knowing Your Starting Point

Having a thorough assessment of your condition at diagnosis and finding the right care are interrelated and essential to optimal treatment. A full assessment can help you determine what constitutes the best physician choice for you, but sometimes it takes finding the right physician before you get a true full assessment.

It is not possible to generalize, for example, what a Stage 4 diagnosis of NETs means until as much information as possible is gathered. Many NET patients have metastatic disease at the time of diagnosis, but where are all the tumors and metastases? How aggressive is their growth (grade), and are they growing in a location that interferes with important functions? Is the tumor releasing hormones (functional) and does it have receptors (a characteristic of the cells that impacts diagnosis and treatment)? Every part of the assessment informs your eventual treatment plan. In many situations, given limited disease and indolent or slow-growing tumors,

even Stage 4 disease can be controlled for years if not decades. However, aggressive tumors, or tumors impacting vital structures, usually require intervening vigorously and with urgency. Patients are always best served by comprehensive assessments that provide the complete picture.

Assessment tools can include biomarkers in blood and urine, tissue analysis (biopsy), and imaging (CT, MRI, and PET or other nuclear imaging). If a certain test or scan has not been ordered for you, don't hesitate to ask your health care provider why. These tools may not all be available at your local care center, and some may not be covered by your insurance without an appeal from your doctor. Tests, biopsies and scans alone may not give the whole picture. In certain cases, your doctor may want to observe your disease status over a period of time; watching  [NET 101 for the Newly Diagnosed](#) can be informative.

Choosing a Provider: The Case for the Specialist

A sailor's wisdom: We cannot direct the wind, but we can always adjust the sails.

It's important to recognize that not all doctors have the latest knowledge or sufficient experience in treating neuroendocrine cancer patients. In neuroendocrine cancer care, it is essential that you find the right specialist to "captain your ship" and direct the course of your care from the very beginning. It cannot be overstated—***you deserve the right treatment by the right team at the right time.*** Therefore, it's important to have someone at the helm who knows the boat, knows the waters, and can adjust the sails for an



"When establishing a treatment plan, it is very important to know as much as possible about the tumor itself—grade, origin, stage, organs involved by the cancer, whether the tumor makes any biochemical substances (hormones) and if the patient has any symptoms from the cancer. Additionally it is important to consider any previous history of cancer and related treatments, as well as the patient's overall state of health."

Boris Naraev, MD, PhD

optimal journey. Specialists in NET have the experience and expertise to apply the appropriate treatment option at the right time for the optimum outcome. The more NET patients they've treated, the more likely it is that they have seen conditions similar to yours. Early consultation with an expert can lead to properly sequenced treatment plans that consider both the present as well as the future. Careful disease management over years is often needed (see Chapter 4).

How do I find a NET expert? Here are some suggestions: Ask your diagnosing physician to help you find a specialist. You may want to engage your primary care physician or a trusted medical professional in the search for a specialist. NET patient organizations can provide information regarding NET centers and NET specialists, and many have links to talks given by various NET experts by specialty or disease type. Contact NET patient support and advocacy groups to learn names of providers in your area and beyond. There are online patient groups organized by disease type that may help you find other patients on a similar path who have received great care in a particular region.

Finding an experienced “captain” to guide your treatment is important for another reason: he or she will have access to the best “crew,” a multidisciplinary group of specialists, each with expertise in a specific area, who contribute to charting your treatment course. Medical specialties that may be represented on your multidisciplinary care team include: pathology, radiology, interventional radiology, nuclear medicine, surgical oncology, medical oncology, endocrinology, gastroenterology or pulmonology. Your care team could also include PAs, NPs, nurses, dietitians, respiratory therapists, counselors, social workers, pharmacists, or patient navigators.

While the multidisciplinary approach is optimal, it may not always be achievable. NET specialists are not found in every medical center or even in every cancer center. Traveling to centers that have NET specialists may not be an option due to economic, health or logistical reasons. Insurance networks may dictate which physicians you can see. You may be able to surmount these barriers and emulate the benefit of a multidisciplinary care

team if you find a local physician who is willing to research on your behalf and seek consultation, review the latest guidelines on NET treatment paths, and refer you to other providers needed for your care or for a second opinion. Out-of-state specialists may offer virtual consultation by phone or video conferencing if allowed by their state medical licensing board. Medical files and discs containing CT, MRI or PET images can be sent to specialists for review. Due to the rarity of this cancer, many insurance plans may approve consultations as needed.

It's best to find someone with whom you feel comfortable talking about your disease and whom



GRADE: *These tumors do not all behave or grow in the same way.*

Grade refers to how fast or how slow the tumor is growing. Doctors use a sample of the tumor obtained through a biopsy or through surgery and examine it to determine how quickly the tumor cells are multiplying. The result is the Ki-67 index or the mitotic index, and the higher the measure, the higher the grade, on a range from Grade 1 or G1 (slower growing) to Grade 3 or G3 (faster growing).

STAGE: *A tumor can start in one place and then spread (metastasize) to other parts of the body.*

Stage refers to how advanced the cancer is--how far it has spread, or traveled, from where it began in the body. Using scans or imaging (CTs, MRIs, or various types of PET scans), doctors can “see” where the tumors are in your body. The stages range from Stage 1 (has not spread) to Stage 4 (spread to other organs or parts of the body).

DIFFERENTIATION: *The structure of the cells that make up NET tumors is variable.*

Differentiation refers to how the tumor cells look when compared to normal cells. Well-differentiated means the cells generally resemble normal cells, and these are usually slower growing tumors. Poorly-differentiated means the cell structures appear abnormally jumbled or disordered as compared to normal cells, and these are typically faster growing, more aggressive tumors.

In lung NETs there are additional classifications: well-differentiated lung NETs are further classified as typical or atypical, with the typical ones being more slow growing than the atypical ones. Atypical lung tumors are sometimes called moderately differentiated or poorly differentiated. Poorly differentiated lung neuroendocrine tumors may also be called large cell neuroendocrine tumors of the lung.

you trust, whether they are an expert or not. If you read about a treatment online or hear about something in a support group, you should feel free to ask questions about what you learned and IF it might be appropriate to consider, either now or later. Do not assume that a treatment or intervention you hear about is appropriate for you but do expect your physicians to listen and advise you.

In choosing a physician, take note of your ability to relate to and communicate with him or her during your initial appointment. Does the physician give you enough time during the visit to understand your situation and appear to listen carefully to what you are experiencing? Here are some questions you might consider asking to understand if they have the necessary expertise in NETs:

- How many NET patients are you currently treating? A low number may raise concerns about experience level.
- Would you be willing to consult or collaborate with a NET expert?
- Are you familiar with and are you willing to consult the latest expert guidelines for treating neuroendocrine tumors by the National Comprehensive Cancer Network (NCCN) and the North American Neuroendocrine Tumor Society (NANETS)?
- Do you have a multidisciplinary team to collaborate with on my case? Will my case be discussed by a tumor board (a regular meeting of specialists who discuss treatment options for cancer patients)?

If the physician is not providing satisfactory answers or is dismissive of you, it may be a sign to move on.



“One of the most important things when patients are going through their NET journey is the honest conversation they need to have with their providers. When you’re able to establish that honesty up front, it really helps to build trust within the relationship. When both sides are able to open up, and listen to each other, you can start to understand each other fully. It really is a journey together to create space for patients to be able to express what they understand, what they want to know and what they want out of their treatment.” Daneng Li, MD

Good Communication Builds Trust and Confidence

Communication is a two-way street, and you can influence the traffic in both directions. As a patient, try to organize your thoughts and questions ahead of communicating with a healthcare provider. Prioritize your questions and concerns. Answer your provider’s questions as fully as you can. Listen closely to what he or she is saying and repeat it back if you are unsure of its meaning. Work toward open and honest conversation, which is not always easy when discussing personal matters.

Other issues that can affect your health, including stress and depression, can arise during cancer treatment and need to be addressed. Be sure to share these and any other concerns with your physician even if they may not seem to be related to your disease. The same goes for embarrassing symptoms like diarrhea and excessive gas. These could be due to a number of factors, including hormone oversecretion, insufficient absorption of enzymes and other nutrients, or changes in your body following a surgical resection. Your doctor needs to know what’s going on with you and what, if anything, changes over the course of your disease in order to adjust your treatment or recommend other remedies that will improve your quality of life.

It is quite common to have difficulty remembering what has been said in an appointment. There is a lot on the line, and the emotional stress can affect your recall. It can be helpful for a family member or friend to accompany you and take notes. With current technology, it is also possible



“It is usually a process to encourage good communication and help patients feel comfortable speaking up. It takes time to earn the trust of the patient and develop rapport. I do ask a lot of detailed questions and take my time to listen to the patient. As well, I personally appreciate when family members come with the patient to a visit, as it helps all of us to enhance communication and navigate through difficult topics.” Boris Naraev, MD, PhD

to record the appointment on your phone or tablet device. Always ask your doctor for permission before doing this. This is especially helpful when a loved one or caregiver cannot attend the appointment and offers the opportunity to review and debrief together at a later time.

Do not assume that all of the healthcare providers on your team are on the same page. Try to confirm that your primary or lead physician is keeping your other doctors informed. You may have to obtain and share your records with them if this is not happening. If the provider uses a web portal to communicate with patients, be sure to set it up and try it out right away. Find out if emails are an appropriate way to ask questions. Learn what each provider's stated response time is so you know when to follow up if you haven't heard back. Ask how you can reach a provider after hours in case you have an urgent question or issue.



"Taking care of neuroendocrine cancer is really a team effort. Unfortunately, communication can be difficult, and we frequently rely on the patient and family to help interface between specialists and local health professionals. Never be shy about following up on documents and reports. Help us by keeping good records and bringing them to your visits." Eric Liu, MD, FACS


Documenting the Journey

Whether you're newly diagnosed or choosing a new care team after a long hard road of sharp curves, U-turns and deadends, it is important to keep track of where you've been.

We recommend you obtain copies of all of your scans, pathology reports and insurance documents and keep a notebook to jot down questions and record answers during your appointments. Organizing the massive amount of information produced by your cancer diagnosis and care will help you communicate more effectively with your health care providers, especially when consultations are needed or a new doctor joins your team. This requires a fair amount of time, persistence and organization. You might delegate a reliable, trusted family member or

friend to help with some or all of this and be your designated recordkeeper, notetaker, scheduler, etc. (See Chapter 6 for more on sharing the care).

There is a lot to remember, and terms are confusing. If you track and record things as you go, you will not miss important information along the way. Here are some record-keeping tips:

1. To capture key information about your disease in one place, find an app or a tool you like, such as NET VITALS from LACNETS.
2. You can use Dropbox, Box, Google Drive, etc., to store and share reports, labs, notes, advance directives and other documents  *Communication and Organizational Tools* in the cloud.
3. Organize every piece of paper related to your care, for example, by year or by practitioner, and keep these documents in one place.
4. Take the same notebook with you to every appointment so that you can refer to your notes from previous visits.
5. Keep detailed records of all communications with your insurance company, including dates and times, the name, title and contact information of the person you spoke with, and the information you received.
6. Ask for and keep at least one CD of every scan that you get. Many NET patients survive for years, even decades, and it is quite possible that earlier scans can be helpful later. Get two copies of scans, if possible, so you can share one with additional providers.

You have a right to all of your records, including copies of your scans. You may have to file some simple paperwork with the medical center's Office of Patient Records. Some medical centers charge for the images, but if you say the scan images are for "continuing care" or speak to your doctor's office, the charge may be waived.

3 NAVIGATING THE MANY DECISIONS INVOLVED IN CANCER CARE

Dealing with a serious disease means making multiple decisions and choices that can be quite difficult. Who do you tell about your diagnosis? How can you handle work and family responsibilities? Who should be your caregiver? How do you navigate all this?

It may help to consider a few things about yourself and how you make decisions. Do you prefer control or do you prefer others to step in and help you make decisions? What type of information and level of detail would be helpful to you? Are you comfortable discussing sensitive things with others, including those close to you?

Steps to Working Through Treatment Decisions

Caring doctors will always support your efforts to understand your disease. Work to foster open, honest communication with them. Share your hesitations and struggles. Don't be afraid to ask questions or request a second medical opinion (or even a third) before making a big treatment decision. Patients who are secure in their treatment decisions often report improved outcomes, including better quality of life. Remember, you are a vital part of your care, and what you bring to the process is the most important filter of all.



“There are so many layers of information, and it takes repetition to begin to integrate it all. We start with questions about diagnosis, treatment options and prognosis. Most of that initially comes from the doctor. That information is enhanced and supplemented by many other sources, including primers like this, websites, and patient support groups. It’s easy for patients to get overwhelmed. The knowledge base is so deep that it’s our responsibility as providers to make sure we supply the information at a time when it can be accommodated and at a time when it’s relevant.” Hagen Kennecke, MD, MHA



“The more quality information you have, the better decision you can make. Working with a specialist helps get more information, detail, and experience about the different treatment options, which can fill out the picture and help you evaluate what is right for you. Such choices can be very personal too. Your thoughts and feelings about treatment choice are critical. The most important thing is to remember that we are here to help you.” Eric Liu, MD, FACS

Following this process may help with your decision-making:

1. Start with yourself. List your goals for treatment and preferences for your quality of life, and anything else that is important to you. Do you prefer to be treated close to home? Do you want to continue working during treatment?
2. List any financial, insurance and logistical considerations that might affect your decisions.
3. Ask your medical team about the effectiveness and side effects of treatment and the time it will take to recover.
4. Ask what else is out there. Clinical trials can be an avenue to therapies that show promise but are still considered to be “investigational.” It is important to remember that statistical data from scientific studies is averaged across a large patient population, and your experience with a particular treatment might be different from the “average.”
5. In addition to getting a second opinion, request that your case be reviewed by a multidisciplinary tumor board if available.

Navigating Roadblocks

While consultations can be extremely helpful, they can also create confusion if your consultants recommend different courses of action. You may feel pressured by loved ones to choose a particular medical intervention. This

can lead to tremendous stress and discomfort. Everyone involved needs to respect your decision—a decision based on your goals and what you can tolerate. Having respectful and caring conversations with your loved ones may help them understand your decision and the reasoning behind it. Social workers and therapists can help navigate these conversations if emotions run high.

You may get many suggestions from friends and family. Whether it is finding a clinical trial, taking a dietary supplement or following a special diet, everyone seems to have an opinion. During this difficult time of adjustment to your rare cancer, unsolicited advice can be a drain on your energy. If so, ask a trusted friend or relative to run interference for you. Or redirect the conversation by saying, “What I really need now is...”

The fear and anxiety that can accompany a cancer diagnosis can be very limiting and hard to overcome. Decision fatigue can set in. Consider asking to speak with a social worker or psychologist if you find things overwhelming and need more help.



“Sometimes I find family members are kind of like the arms-length, third-party adjudicator that is needed. They are so key in helping to make some of these tougher decisions. I find that the primary local oncologist and the primary care provider can be really helpful as well.”

Hagen Kennecke, MD, MHA

Advance Directives

As adults, there are decisions that we all need to think about in the case of sudden impairment due to accidents, or health crises, or serious illness, but these are often neglected until it is too late. **Every adult in a family should prepare advance directives.**

Advance directives allow you to communicate the type of medical care you want if you become too sick to make your own decisions. Yes, preparing these documents ahead of time is a chore, but think of it as a gift to your family members. Without an advance directive, they might have to decide what is best for you without your input.



BEING READY IN CASE OF EMERGENCIES

It is always advisable to have an “emergency preparedness kit” at the ready. Here are some important items to keep in your kit:

People to reach:

Carry emergency contact information, including treating physicians and their contact information.

Emergency bracelets or cards:

Wearing an emergency bracelet or keeping an emergency card in your wallet or billfold can alert first responders including police and paramedics to any life-threatening conditions you have, including allergies and risk of carcinoid crisis, in case a medical emergency prevents you from communicating.



Communication and Organizational Tools

Smart devices:

Smartphones and smart devices often have a feature that allows you to set up your emergency contacts and add essential information such as medical conditions, allergies, and current medications. This allows first responders to access important medical information from the lock screen, even without your passcode.

“Go kit” or “Go bag”:

Pack a casual travel bag with supplies you’d need if you were admitted to the hospital, such as a spare change of clothes, extra medications, a flash drive or other record of your current medical information and history, people to contact in case of emergency, and your advance directives.

Be prepared to be asked if you have these documents when you go in for a surgery or a procedure requiring anesthesia.

- A living will states your wishes should various medical scenarios occur, like stroke or coma.
- A medical power of attorney (sometimes known as a durable power of attorney), appoints someone as your health care proxy or a healthcare representative to make healthcare decisions for you when you are unable to speak for yourself. A proxy can be a family member or trusted individual who will carry out your wishes. Your proxy is also allowed to access your medical records.

You should also let those close to you know where your important papers are stored and what your

wishes are for burial, memorial services or celebrations. Conversations surrounding these difficult decisions are sensitive and deeply personal, and there are cancer organizations that provide resources or counseling to help you have these conversations with loved ones.



Advance Care
Planning

4 THE LONG HAUL: MANAGING NETS AS A CHRONIC DISEASE*

**For the most part, this section focuses on the journeys of those with slow(er) growing disease and not all will apply to those with more aggressive, high-grade NETs and NEC. You can find a resource focused specifically on high-grade neuroendocrine cancer at thehealingnet.org/high-grade-neuroendocrine.*

Coping with a serious disease, especially if you will always have it, is very challenging. The terrain can feel foreign until you adjust to where you are now. It is important to watch for and manage issues that are related but not directly tied to your cancer. Such difficulties could include sleep problems, digestion issues, nutritional deficiencies, pain, fatigue, as well as anxiety and depression. Do not be afraid to ask your doctor for a referral to other providers for help with these issues.

Surveillance and Monitoring

Most likely you will be dealing with NET cancer in some way or another for the rest of your life. It is important to understand that NETs recur very often, sometimes years later, even if a patient is determined to have no evidence of disease (NED). Patients who are living with existing disease should be checked at regular intervals for any changes. A provider with NET expertise will know what to look for and how often to check.

Surveillance is watching for disease recurrence once all visible signs of the cancer have been removed by surgery or other therapy and the patient is considered to be NED. Even in this case, there should always be a physician-monitored schedule of surveillance. This schedule of surveillance may

differ in how (which modalities) and when (how often) depending on individual circumstances.

Monitoring is watching existing disease by comparing the results from the latest tests and scans to prior results. How you are monitored will depend on the type of NET you have and the location and extent of the cancer in your body. It may include blood tests, 24-hour urine collections, and imaging scans such as CT, MRI and/or nuclear medicine scans such as the Ga-68 or Cu-64 DOTATATE PET scan. If you have any questions about your monitoring plan, ask your doctor. It is important to have confidence that you are being managed well.

Experiencing bouts of anxiety can occur as part of having these regular scans and check-ins with your oncologist. Support groups often discuss the ups and downs of living between scans. It is part of the reality that you will adjust to in your own way, which is not to say it is easy. Keep in mind that the same adage “knowledge is power” is true here as well as during your first diagnostic work-up. When you are worried, remind yourself that early detection of changes leads to earlier intervention, which offers the best shot at controlling disease!

Functional Tumors: Extra Baggage

A certain proportion of NET patients will have to adjust to living with symptoms that the cancer is actively causing. NETs can upset your normal hormone balance; your doctor can help discern if your symptoms result from your tumors and, if so, how best to address them. It can take a long time to sort this out, which can be frustrating, but keep at it.

NETs that actively produce and release **excess** hormones into the body are called **functional tumors**. It is generally understood that about 20 to 35% of all patients may have some level of functional disease. This causes imbalances that affect your body and how it functions and may create dangerous, health threatening issues.

Non-functional tumors do not cause imbalances, either because they do not release hormones or they release such small amounts. However, it has been observed that some tumors that are originally non-functional can change after a while and begin to produce and release hormones.



FUNCTIONAL TUMOR SYNDROMES

CARCINOID SYNDROME

usually arises from NETs in the small intestine or lung due to the overproduction of serotonin, which may trigger severe diarrhea, dry flushing of the skin, night sweats, and/or wheezing. Carcinoid syndrome diarrhea and its treatments can lead to pellagra, a niacin-deficiency disorder.

ZOLLINGER ELLISON SYNDROME

results from a NET of the pancreas or duodenum and produces excessive levels of the digestive hormone gastrin. This tumor is also called a gastrinoma. Symptoms include diarrhea, severe ulceration of the stomach or small bowel, heartburn and abdominal pain.

GLUCAGONOMA

usually begins in the pancreas. The overproduction of the hormone glucagon raises the concentration of glucose and fatty acids in the blood and can cause diabetes, severe weight loss, severe rashes, and blood clots.

INSULINOMA

almost always begins in the pancreas. It overproduces the hormone insulin. Uncontrolled insulin levels can cause low blood sugar (hypoglycemia) which can lead to serious medical conditions.

VIPOMA

usually arises in the pancreas and may overproduce a hormone that can cause prolonged watery diarrhea and dehydration. Patients may experience muscle weakness, nausea, vomiting and crampy abdominal pain.

PHEOCHROMOCYTOMA

arises in the adrenal glands and can release hormones that may raise blood pressure and cause heart palpitations, headaches and excessive sweating.

PARAGANGLIOMA

appears in the head, neck, or torso and may secrete hormones that can cause episodes of high blood pressure, a rapid heartbeat, sweating, headache and tremors.

Excess hormones can cause a myriad of symptoms referred to as a syndrome. Symptoms will differ depending upon where the tumor arises and which hormone is overproduced. The most common is carcinoid syndrome caused by excess serotonin. Patients will differ in the frequency and intensity of symptoms they experience. Some may require constant management of their symptoms while others may experience symptoms only occasionally. If you have any of the syndromes that can be caused by a functional NET, you may need the attention and care of a knowledgeable endocrinologist (a specialist in the endocrine, or hormone-releasing system) to help your oncologist sort out, treat and monitor your symptoms.

A typical treatment for the syndromes caused by functional NETS is prescribing somatostatin analogs (SSAs). Your doctor can discuss all the available variations of these medications with you. A medication called telotristat ethyl can be given along with SSAs to help control carcinoid syndrome diarrhea that is not managed by SSAs alone. In some cases, surgery to remove as much of the tumor load as possible is recommended. This is referred to as de-bulking surgery, and this can help reduce the effects of functional tumors.



[Carcinoid Syndrome and Other Symptom Management](#)



“Finding ways to cope with the anxiety and worry that can accompany carcinoid syndrome may aid in decreasing symptoms and how much they affect your life. Incorporating self care activities to reduce stress, such as journaling, enjoying your favorite hobby, spending quality time with loved ones, meditation and/or just resting and pausing when needed, can make a difference. These things, coupled with your medical interventions, can greatly improve your quality of life.”

Dana Stafford RN, BSN

Carcinoid Crisis and Carcinoid Heart Disease—Hazards in the Road

Carcinoid Crisis is an uncommon dangerous situation that arises from a sudden over-release of hormones from your tumors, causing intense flushing, wheezing, and dangerous fluctuations in blood pressure. It is different from the excess hormone release that causes carcinoid syndrome, and even if your tumors are non-functioning, you are at risk. Surgical or dental procedures require anesthetics and can

involve severe stress to the body, both of which are known causes of crisis. Always reduce this risk by informing your doctor or dentist of your situation prior to surgery or dental procedures. The swift administration of octreotide and/or other medications (held on standby during procedures) can treat this crisis should it occur. Octreotide can also be administered preventively during invasive treatments to avoid this complication.

Carcinoid Heart Disease is one of the major features of carcinoid syndrome and occurs in 50 to 70 percent of people with carcinoid syndrome. It is caused by excessive release of serotonin, usually by metastatic tumors in the liver. When carried through the bloodstream into the heart, the excessive serotonin can cause scarring of the heart's inner lining, including the two right heart valves, the tricuspid and pulmonary. Symptoms may or may not be apparent and can include: fatigue, difficult or labored breathing, and/or fluid build up and swelling in the body. It is important for you to report ALL of your symptoms to your doctors. This condition may be treated by medications and, if needed, cardiac surgery.

Emotions as Part of the Journey

While it is heartening to realize that it **is** possible to live a long time **with** this disease, and to live well, it is also daunting to wrap your head around the fact that you will always have cancer and that it needs to be managed and controlled. It's important to give your emotional and mental health needs the same level of attention that you give your disease. Don't be hesitant or embarrassed about asking for help when things become too heavy.

Since slow-growing cancers typically do not benefit from chemotherapy and are treated in other ways, NET patients do not have the visible signs of cancer treatment, like hair loss. They also may remain stable for a number of years—something that people don't associate with cancer. While that is a welcome scenario (comparatively), it can be frustrating to patients when those around them, including those closest to them, don't recognize or acknowledge the worry and discomfort of living with cancer. The familiar term "remission" really does not apply to stable, progression-free NET cancer, and sometimes this is difficult to explain.



"All patients with a neuroendocrine tumor should have a baseline echocardiogram; the echocardiogram is 100% sensitive and specific for diagnosing carcinoid heart disease, and that test can determine the presence or absence of other important cardiac problems which, when treated, can prolong one's survival."

Jerome S. Zacks, MD



THE FIVE E'S to Help with *Managing Carcinoid Syndrome Symptoms*

EATING

Large meals, spicy foods, and foods high in nitrogen-containing compounds called amines can trigger symptoms of carcinoid syndrome. Tomato-based foods, caffeine, chocolate, nuts and raw vegetables are common triggers.

EXERCISE

This trigger is highly variable from person to person, but in general physical stress may activate symptoms. The trick here is not to overdo. If you are not used to a particular exercise regimen, take it slowly and work up your tolerance.

EMOTIONS

Strong emotions such as anger, stress and anxiety can trigger symptoms. While it is impossible to completely avoid stress in everyday life, patients with carcinoid syndrome should work to reduce stress levels.

EPINEPHRINE

Certain medical or dental procedures may require numbing agents or anesthetics, which could contain epinephrine. In small doses it is usually quite safe, but epinephrine could trigger symptoms. Inform providers of your carcinoid syndrome diagnosis so they are aware and can consider alternatives.

ETHANOL (ALCOHOL)

Some people cannot tolerate any alcohol because it can exacerbate carcinoid syndrome. Monitor your own reaction and adjust accordingly.

Supportive Care Throughout the Journey

If you are lucky enough to be near a center that offers palliative care, integrative medicine and/or survivorship programs, you may want to explore how they might serve your needs. Eligibility for these programs begins at diagnosis and can provide the most benefit if taken advantage of from the start, but you can access them and enjoy their benefits at any point along the way.

Palliative Care

Palliative care is often called symptom management. It is not hospice care, rather it is focused on improving quality of life for people with serious illness. Experts in palliative care can help with things such as relaxation techniques, psychological counseling, nutrition, sleep issues and pain control.



“I definitely think that early palliative care helps people. We’re not necessarily seeing people live longer, but their quality of life metrics are significantly improved.

Patients need an outlet to be able to talk about what they’re dealing with. I would argue that everybody with a cancer diagnosis needs professional psychological assistance. I bring that up in conversation during the first one or two visits. ‘Cancer is stressful. What are you doing to help with the stress? If you don’t have a patient support group, here are some options. If you’re interested in meeting with counselors, here’s how to get in touch with them.’

For end-of-life care, I ask myself: ‘Would I be surprised if this person died within a year?’ If I wouldn’t, then we need to talk about it together. One thing we’ve started to do at diagnosis is to say, ‘If we’re going to have bad news, we will need to have a “serious illness conversation.” How do you want to have it?’ It’s really helpful for doctors to know how a patient wants to talk about these things.”

Scott Paulson, MD

Integrative Medicine

Similarly, integrative medicine can address and help alleviate other issues associated with serious disease by promoting stress reduction and relaxation through such offerings as acupuncture, exercise classes, mindfulness and massage.

Survivorship or Wellness Programs

These programs are designed to help patients manage the transition from active treatment to recovery. They generally take an extensive assessment that details the patient’s diagnosis, treatment and monitoring protocols, any physical and emotional needs resulting from treatment, as well as the patient’s hopes and desires. The assessments are periodically updated.

While formal palliative care, integrative medicine and survivorship programs may not be available in your area, your primary physician or a hospital social worker might help you find providers and services that can address your needs.

Supportive End of Life Care

Hospice Care

Some cancer patients and their families will be confronted with one of the most difficult decisions of all: the decision to stop treatment. Hospice programs are invaluable in helping to shepherd families and their loved ones through this time by providing a medical team, equipment, home or inpatient treatments, hospice pharmacy, assistance with personal care, grief, end of life planning, spiritual guidance, and counseling. Support and care are provided to patients as well as their family and friends who are helping on the journey. Some hospice programs provide music, pets, massage, aromatherapy, or other complementary therapies.



“Hospice care is not about giving up; it is about shifting our focus from the exhaustive regimen of treatment to focus on having as many good and pain-free days as possible. You might be surprised to know that the word hospice comes from “hospitality.” The root idea is “a safe place of rest for the weary traveler.” The goal of hospice care is to pay attention to the quality of your days. Hospice will do all they can for you to be comfortable, alert, and able to enjoy life as much as possible. Most hospice care is provided in your home or that of a loved one, but may include care in a hospital, nursing home, or a hospice facility if available.

Hospice care does not provide curative treatments, yet hospice patients tend to live better days, and they may live more days. Hospice patients tend to feel happier because they are able to regain some of the control of their daily schedules and living that may have been lost during aggressive treatments. Family members and friends may feel more comfortable during visits.

Hospice care can provide different healing: the joy of living life each day as fully and pain free as possible.”

Gene Lovelace, Hospice Chaplain
NET Spouse / Caregiver

geared toward stress reduction. Exercise classes can be fun and are wonderful ways to connect with others and relieve stress. Spiritual communities can be extremely comforting to their members, providing assistance and emotional support, as well as continuing to offer purposeful opportunities to help others, which can be very gratifying.

Prioritize YOU

Self-care includes being honest with yourself about your own needs, especially those involved in getting you to your goals. This may involve setting limits on your time and responsibilities with both family and friends and choosing to make time and space for yourself when you might have neglected to do this in the past.

5 ARRIVING AT A WHOLE-SELF PERSPECTIVE

The Importance of Maintaining Good Health

Protecting your health is more important now than ever before. To maintain your ability to live well after treatment it is important to improve, or avoid developing, other health conditions to the extent this is within your control. Do you smoke? Do you have a sedentary lifestyle? Do you have a poor diet or drink to excess?

One positive effect of making changes to improve (or maintain) your health is that this commitment to better health can also boost your emotional wellbeing. Even doing small things to take care of yourself and making time for yourself can increase your confidence and feelings of self-worth.

Many wellness and cancer patient support programs offer meditation, yoga and other classes

If you have an issue that needs attention, or a self-improvement goal, use the “4 I’s” below to help you focus on what is most important to you right now. The goal of such an exercise is to increase self awareness and prioritize goals for improvement, whether spiritual, emotional, physical or interpersonal.

The 4 “I’s” to a Healthier Life

- **Identify:** What issues am I struggling with? What would I like to improve?
- **Investigate:** How can I address my issues? Who can help?
- **Initiate:** Develop a plan. Take the first small steps.
- **Integrate:** Make these changes a part of my life

As you go through the steps, consider writing them out and sharing your responses with a friend or loved one. Support can be a powerful way to reinforce your commitment to change. If you have access to a professional like a certified health coach, counselor, or social worker, they can help you with this self-assessment.

It is important to take your self-care, especially exercise, at a pace that is sustainable. Being a patient can be exhausting in many ways, and you might find yourself with limited energy even after treatment ends. You would not be alone in this. The most common symptom and the one identified as most troublesome to all cancer patients, including NETs, is fatigue. Yet fatigue will get worse if ignored. One great way to combat it can be to **get moving**. Moving your body can hasten healing and help you recover strength that may have been lost during treatment and recovery.



“If you have fatigue, it needs to be carefully evaluated by your care team. Fatigue may be related directly to the cancer itself and/or to the cancer treatments that patients might be receiving. There may be more than one cause of fatigue to be addressed, such as:

- *Underlying medical conditions, for example, low thyroid gland function or low B12 levels—these can be treated to improve energy levels.*
- *Poor nutrition—sometimes evaluation by a dietitian might be needed to make sure you are getting proper nutrition.*
- *Deconditioning (not being able to exercise)—try to remain active.*
- *Trouble sleeping—try to optimize your daily schedule so that you will get enough sleep at night. Limit daytime naps.*

Other ways to help combat fatigue include:

- *One could try to conserve energy. For example, delegate some of your responsibilities to others or schedule your activities during times when you are at your peak performance.*
- *Psychosocial approaches, for example, cognitive behavioral therapy, help some people.*
- *Other approaches include yoga, acupuncture, physical therapy and light therapy.*
- *Occasionally, in cases of severe fatigue that cannot be corrected otherwise, doctors use medications (for example, methylphenidate) to help patients stay alert.”*

Boris Naraev, MD, PhD

Of course, you will need to check with your physician before starting any activities after surgery, treatments or interventions. But once you’ve been cleared, just start, one step at a time, maybe with short walks inside your home. Any gentle movement builds a foundation for more exercise over time. Cooking and housework can be exercise—put on your favorite tunes and move to the music!

6 AT THE INTERSECTION OF GIVING AND RECEIVING CARE

What Is a Caregiver?

In the cancer world, caregivers are thought of as anyone helping a family member or friend living with cancer. They are usually unpaid loved ones who take up any number and types of tasks, such as:

- Assisting with activities of daily living, e.g., cooking, cleaning and medication management
- Providing emotional support and companionship
- Researching NET care and treatments
- Advocating on behalf of the patient, taking notes and asking questions at medical appointments
- Navigating the healthcare system – scheduling appointments, collecting and reviewing labs and reports, filling prescriptions
- Managing insurance claims and household finances
- Connecting with the NET community for education and support
- Coordinating meals, travel, driving to appointments
- Communicating with the support team (other family and friends) and with the medical team

Communication: The Key to Defining Roles and Expectations

It would be ideal to sit down and have an open dialogue with loved ones to establish roles, expectations, and values soon after your diagnosis. Newly diagnosed NET patients need to be given a safe space to express what matters most to them, who they want on their care team, and how they would like to be supported. Caregivers may find it challenging to know how to switch among various roles and responsibilities. Open and honest dialogue about preferences and expectations can help establish care roles in a way that is sustainable and that preserves or even deepens relationships.

A Cancer Diagnosis Can Strengthen or Stress Primary Relationships

The diagnosis of cancer can affect familiar, traditional and expected relationships. Assumptions on the part of medical providers or the patient's community about the roles and responsibilities of loved ones, such as spouse, parent, child, or sibling, can complicate things even further. While a cancer diagnosis may work to bring people closer together, it is also true that it may be the first time spouses have ever been in such a challenging situation together. Expectations may differ. Sometimes the spouse wants to be the caregiver while the patient does not want their spouse to be the caregiver—or vice versa. When caregiving places an undue pressure on a relationship, it may make sense to turn outward for caregiving help, such as to home health care or other professional services.

Establish Circles of Care

Newly diagnosed patients can be buoyed by offers of help from their community, friends and family. Sometimes it is hard to establish responsibilities and boundaries. One way to think about this is the “Ring Theory,” described in the LA Times op-ed article, “How not to say the wrong thing,” by Susan Silk and Barry Goldman, where the patient is at the center of an expanding series of support rings. The inner ring of support includes the person or people closest to the patient, such as the person's significant other, par-

ent, sibling, child, or best friend. In the next ring are family members and true friends who can be relied on for emotional support, and so on. The core concept is that a person can say anything to those in rings farther out from them but are to provide only support and comfort to those at the same distance from or closer to the center. One challenge is to let people know what kind of support you want from them.

This concept of rings can help you organize assistance. Those in the inner rings of your care circle provide physical help, daily care, and emotional support. They can help coordinate other supportive care duties with those in the outer rings, for example, delivering meals and groceries or driving the patient to appointments.



*Giving and
Receiving Care*

For Those Living Alone: Developing a Community of Support

You may live alone, but you are not alone! While you may be hesitant to ask, know that it makes others feel good to be able to help someone in need. Patients are often surprised at the kindness and support that they encounter from friends, family and community.

Consider these ways to organize and connect with those who wish to support you:

- Managing communication using a website or other system that lets you share mass updates.
- Creating a support circle or holding a “share the care” meeting
- Attending a NET support group that can provide information, education and networking with other NET patients and providers
- Engaging community and social service agencies that provide supportive programs and care for those affected by cancer
- Seeing a social worker at your medical center for additional resources



*Giving and
Receiving Care*

A Special Section for the Caregiver: Ways to Provide Support and Be a Better Caregiver

As a caregiver, you may feel overwhelmed and unsure of how to best support your loved one on this NET journey. While we recognize that each caregiver is as unique as each patient, here are some valuable ways you can support your loved one on both a practical and emotional level:

Learn to “speak NET.”

Learning to speak the unique language of NET empowers you to be part of the conversations with medical providers. You will be a stronger companion and champion for the patient if you understand the terms used when symptoms, treatments and scans are discussed. At medical appointments, you can ask more educated questions and better understand what the doctor is telling you.

You are not alone— Engage your network.

Utilize communication and organization tools to involve others in circles of care.



*Communication and
Organizational Tools*

Find a balance between doing and being.

Instead of asking “How do you feel today?” you might consider asking your loved one “How can I help you today?” in order to proactively and collaboratively engage in care. Though you naturally want to ease the patient’s pain and suffering, sometimes the only—and best—gift you can give him or her is to be a comforting presence and simply be still and listen.

Preserve your own identity and boundaries.

It hurts to see your loved one in pain, but the patient’s suffering is distinct and different from yours. It’s OK to empathize, but immersing yourself in pain will not ease the patient’s suffering. It will only make you a less effective caregiver.



“Caregivers can struggle with feelings of isolation or depression and experience physical and emotional fatigue. Part of your journey as a caregiver is learning to give yourself a break.

Release any shame or blame you may feel or others may imply.

- *Your loved one’s cancer is not anyone’s fault. Delays or mistakes by healthcare providers are not your or your loved one’s fault. Other people don’t have a right to question medical choices made and treatment paths followed. Focus on what you can do and not on what you can’t change.*

Make space for self-care. Taking care of yourself will allow you to better care for your NET patient.

- *Take care of your own basic needs including nutrition, physical activity, sleep and stress management.*
- *Address your own health issues. Keep up with your own preventative health maintenance including annual physicals, recommended screening tests, and vaccinations.*
- *Acknowledge your own suffering and experiences. While you are not the one living with cancer, you are affected by it. It may help to talk to a therapist or social worker.*
- *Remember what matters to you and carve out space for yourself. Find some time for things that spark joy, release stress and bring energy.*

Build your own support system.

- *Create your own circle of care. Make an effort to establish and maintain relationships that will provide you with necessary emotional support, assistance, and enjoyment as you care for your loved one.*
- *Seek and accept help from friends, family or professional caregivers.”*

*Lisa Yen, NP, NBC-HWC
NET Spouse / Caregiver*

7 NAVIGATING INSURANCE AND THE COST OF CARE

Livestrong Foundation found that close to 60% of cancer survivors they surveyed in 2015 faced financial problems and felt financially stressed. Even more feared future financial problems. This situation is often referred to as “financial toxicity,” and the burden on cancer patients is real. The National Cancer Institute lists effects of financial toxicity on patients that include not taking medicine as directed and experiencing more pain and more symptoms. See Triage Cancer’s “Checklist to Minimize Financial Toxicity.”



*Legal, Insurance and
Financial Challenges*

Having access to quality insurance coverage is vital to someone diagnosed with cancer in the U.S., and you will need to quickly get up to speed about your health insurance plan because unexpected bills for testing and treatments add up fast. Imagine navigating a major city’s downtown grid for the first time without the benefit of GPS or a decent map. Our goal in this final chapter is to provide some guidance and resources to help you steer clear of insurance and financial potholes and help reduce anxiety around these matters so you can focus on healing.

Health Insurance Matters

The current law governing all individual and group insurance plans (with a few exceptions) provides several rules important to cancer patients. First and foremost, the Affordable Care Act (ACA) protects your right to obtain coverage despite pre-existing conditions, and companies cannot cancel an existing policy after a person is diagnosed. The ACA also removes lifetime caps or coverage limits. This is crucial for many rare disease cancer patients, especially those with slow-growing disease, who may live a long time and require regular monitoring and costly treatments. Additionally, plans now provide coverage of routine costs while participating in clinical trials.

Whether insurance is through your employer, obtained through the ACA exchange or purchased privately, health insurance contracts generally run year to year, and you will need to know your annual renewal date. This is the time to determine which plan or option available to you best suits your needs. Varying costs for deductibles, co-pays, in-network and out-of-network care and individual and family out-of-pocket maximums can each move the cost needle up or down depending on a person’s situation. If you don’t understand how the “patient responsibility” costs are figured, ask for some clarification from your insurer or employer’s HR department until you do understand how your financial responsibilities will add up. Cancer patients in active treatment frequently meet their full deductible each year. The maximum out-of-pocket for any non-Medicare insurance is set nationally, and for 2021 the amount is no more than \$8,550.

High-deductible plans can have a low monthly cost but could be quite costly overall in the face of cancer treatment. Patients with long term health care issues would be wise to avoid the new trend of “skinny” plans and short-term policies due to their very limited coverage and high patient responsibility costs. Some states actually ban these policies. Health maintenance organizations, or HMOs, are often touted as ways to hold down consumer health costs but they can have restrictive networks and rules that can make it very difficult—if not impossible—to get a second opinion or care from neuroendocrine specialists who are out of your network.

Many private insurance companies are offering case managers (often nurses) or patient navigators to help their insured navigate care and coverage issues. These services can be very helpful in streamlining the pre-approval process that your doctor or hospital is required to obtain. Call your plan’s administrator to inquire whether case manager services are available and determine if they can be helpful for your NET care.

The best way to keep yourself financially secure is to stay covered and to acquire the best coverage available. We must also recognize that some cancer situations may lead to changes in employment. If you resign, get laid off or let go by your employer, under federal law you are entitled to COBRA benefits (Consolidated Omnibus Budget Reconciliation Act of 1985). Rules vary from state to state as to the length of time you can carry COBRA coverage. COBRA plans are available for a fixed number of years and match your employer's coverage; once that period is over, you will be offered a "guaranteed issue plan" if you have not already purchased other insurance.

Bumps in the Road

Insurance claims do not always proceed automatically or smoothly through the system. Here are some issues you might encounter.

PEER TO PEER

Peer to peer requests are calls between your doctor and a doctor from the insurance company to discuss why the testing, imaging or treatment prescribed is medically necessary. These can occur after insurance denials or occasionally prior to further action by the insurance company. You and your doctor have the right to request that the "peer" from the insurance company be knowledgeable about NETs and/or have comparable expertise as your doctor. In some cases, an insurance company case manager or patient navigator may be able to offer preliminary assistance to help you avoid these requests and coverage denials.

DENIALS

Denials are not uncommon in NETs. Financial toxicity is a real fear when an insurance company refuses or denies coverage of a request by an individual (or his or her provider) to pay for health care services obtained from a health care professional. In this instance, your insurance contract will stipulate what you need to do to appeal that decision. You must follow up on all denials to learn exactly what the issue or situation was that caused it. Here are some common scenarios—

- **Wrong code:** A billing office may have entered the wrong diagnostic or treatment code and you can find this out by a phone call to your insurance company or you may see it noted on your Explanation of Benefits (EOB) statement. Sometimes a simple re-filing of the claim with the correct diagnostic code is all that is needed.
- **Not medically necessary:** When a test or treatment is deemed not medically necessary you or your doctor will need to appeal. Keep in mind your insurance is a business contract, and you need to understand what that contract or policy covers, what your rights are, and how the appeals process works. Keep your complete statement of coverage on hand and request one if you cannot locate it.
- **Experimental:** Sometimes when a treatment or diagnostic tool is approved by the FDA, it takes time for insurance companies to "catch up" and often the private carriers wait for Medicare to approve before they will consider it established. This denial will likely require the help of your doctor or even further steps to prove it's no longer experimental (or in clinical trial).

APPEALS

Know exactly what your appeals process is before you make the phone call or write the email or letter as most appeal processes have specific time limits for each step once an appeal has started. Don't be caught off guard. This appeals information and what your insurer is contractually required to cover is contained in your full policy.

- Learn to write a great appeal letter. Examples of appeal letters and more information about navigating coverage denials are available online.
- Search NET organizations online for educational articles and videos regarding denials and appeals. The information can help you better understand the appeals process and

how to get the coverage that you have paid for and that you have a right to receive.

- Contact your state's Insurance Commission for difficult issues and concerns relating to your coverage. The insurance commissioner is a state-level position in all 50 states and duties vary state to state, but their general role is as a consumer protection advocate and insurance regulator. Non-profit organizations like the Cancer Legal Resource Center are also a valuable resource for insurance related issues and other legal rights of people with cancer. See resources.



*Legal, Insurance and
Financial Challenges*

Medicare

Medicare has a lot of layers, and you will need to make decisions about which road to take to build your own coverage. We will attempt to provide the most pertinent information on what might impact a NET cancer patient. However, please see Medicare.gov for the best in-depth and accurate information.

Everyone 65 and older (and everyone who has been on SSDI for two years) is eligible for Medicare. You should review your options for how you receive your benefits well ahead of your eligibility. These choices may dictate how and where you receive your cancer care. To explain what you need to be aware of and consider as you make your selections of coverage, you must first understand the mechanics of Medicare coverage.

If you are Medicare eligible, you will first have to decide between receiving Original Medicare or acquiring a Medicare Advantage plan. If you opt for Original Medicare, you will likely add Medicare Supplemental Insurance (aka a Medigap plan) which will cover expenses that original Medicare does not, such as the 20% coinsurance responsibility. If you have insurance through a pension or union retirement program, this insurance can act as your supplemental insurance.



MEDICARE FACTS

PART A

is Hospital Insurance, and is administered by the government.

PART B

is Medical Insurance, and is administered by the government. It is important to note that if you do not sign up for a Part B plan when first eligible, there may be a lifetime premium penalty added to the cost of this required coverage

**Original Medicare refers to Part A and Part B together.*

PART C

is known as Medicare Advantage, these are plans administered by private companies that replace Medicare Parts A and B, and usually Part D (Rx coverage). In the case of these plans, Medicare pays private companies to administer individual Medicare program benefits. The companies then market their various plans to Medicare-eligible individuals.

PART D

is Prescription Drug Coverage. ((See Medicare Part D Drug Plans on p. 20.)

If you have a pre-existing condition, like cancer, it is important to get on board in the first six months to guarantee the cheapest rate for Medigap policies. This initial pricing is offered to every enrollee for a period of 6 months after the start of your Medicare eligibility. If you seek a supplemental policy later on you could be subject to medical underwriting which means the company issuing the policy can assess your health status and pre-existing conditions and charge you accordingly for the policy or perhaps reject your application altogether.

If you travel frequently in the US, or have doctors in different locations, Original Medicare offers the widest possible network (basically the entire US) for eligible care. This could also ensure that consultations with NET specialists are easier to obtain.




READ THE FINE PRINT

Regardless of what type of Medicare policy you have, if you are handed a form at the doctor's office or clinic with a box that indicates you will be responsible for whatever Medicare doesn't cover...DO NOT CHECK THE BOX. All Medicare providers agree ahead of time to take whatever Medicare pays. If you don't check the box, you're still going to receive the care and they can't legally bill you or charge you for the balance. But if you check that box, you most certainly will get their bill.

Medicare Advantage (MA) plans are packages of insurance benefits offered by different companies, and they can differ widely in terms of which services are covered and their care networks. Many are HMO plans that require a referral before seeing a specialist. Medicare Advantage PPO plans, if available, do not require referrals for specialists and usually have broader networks, so they are likely to be a better match for cancer patients than the HMO plans. While MA plans may have perks and cover all or some costs of services (such as vision or dental) not usually covered by Medicare, it is important to read the fine print and evaluate risks versus benefits. Also, be aware that year to year, the services, networks and medications covered by MA plans are subject to change.

Most importantly, if you want to leave the MA plan and move to Original Medicare, you may find it cost prohibitive to get a supplemental (Medigap) policy. You can be subject to medical underwriting which is always a risk for cancer patients. If you are likely to need treatment or expensive imaging in a given year, it is important to compare your possible expenditures for co-pays, deductibles, and yearly out of pocket maximums in the MA plans to

the 12 month cost of a supplemental or medigap policy to determine which coverage is the better overall bargain.

“Choosing the Wrong Insurance Could Kill You” is the title of an article about a study from Yale that specifically looks at Medicare Advantage Plans. This research zeroed in on how insurance plans can appreciably influence the **survival** rate of enrollees or, to put it another way, their **mortality** rate. The study shows consumers aren't well informed about how plans impact their health outcomes and the authors noted that insurance companies “have way too little incentive to invest in things that will actually make people healthier.” This can all sound incredibly complicated, but there are unbiased resources available to help you. See Unbiased Help below and  Medicare see resources.



UNBIASED HELP

in Choosing Medicare Coverage

State Health Insurance Assistance Programs (SHIP) are available in every state. They provide local, independent, government counselors who can assist you in choosing the right plan for you.

To find a SHIP counselor in your area, go to: shiptacenter.org

One of the most helpful services on the Medicare.gov website is the Medicare Plan Finder. This interactive tool will help you find every plan offered in your area and provide in-depth comparison information. You may isolate your search to drug coverage under Part D plans; you can plug in your medications and get immediate information on which plans offer the best value and coverage for your needs.

To access this tool, go to: www.medicare.gov/find-a-plan

Medicare Part D Drug Plans

Medicare Part D drug coverage comes from private insurance companies, with Medicare paying a portion of the costs. 70% of people on Medicare have a Part D plan. You need to sign up as soon as you're eligible—if you don't, you may have to pay a late enrollment penalty later when you do enroll. Be sure the drugs you need are on the Part D plan you select or you could face thousands of dollars in out of pocket costs.

Non-Medicare Drug Coverage

For those not on Medicare, most insurance plans will cover prescription drugs; however, the copays, deductible, and out-of-pocket maximums can vary from policy to policy, and year to year. Check your drug coverage at every renewal for changes in coverage in the event that you have some choice in the coverage.

Assistance with Drug Costs

Most brand name drugs will have some type of copay assistance program offered by the manufacturer that reduces the cost of the drug to typically under \$50. You may need to do a web search to find the program for the drug you are considering. These plans may have little or no income verification but in general are not available to those on Medicare. You may also find additional financial support for medication and care through private foundations. One such program providing foundation assistance *specifically for NET patients* is the Lois Merrill Foundation.

For generic drugs, and limited brand name drugs, you may wish to use a program like GoodRx that may provide the drug at a lower cost than what your insurance will provide. You just have to be sure you don't use Medicare to pay at the same time. NeedyMeds is a 501(c)(3) national nonprofit that connects people to programs that will help them afford their medications and other healthcare costs.



Medication Costs

Employment Protections

Depending on your circumstances, you may need to research employment protections and laws pertaining to people with cancer and/or their families. These programs are governed by both state and federal statute so what is available to you will depend on where you live. The Family and Medical Leave Act (FMLA) is a federal program that provides leave protections for patients and family (caregivers). Laws pertaining to (patient) employment protections as well as resources available for cancer patients are listed by state at the Triage Cancer website.



Legal, Insurance and
Financial Challenges

Social Security Disability

If you qualify, the Social Security Disability Insurance (SSDI) program pays benefits to you and certain family members. You qualify for this program if you are no longer able to work, you have worked long enough and recently enough, and you paid Social Security taxes on your earnings. Refer to this government website for all the details: ssa.gov/benefits/disability/.

While each case is different, many NET patients who are eligible based on employment history generally meet the medical qualifications for SSDI, especially if you have liver metastases that cannot be surgically resected. In general, and very simply, the requirements are that you will live longer than a year, and that the condition is not curable. Those who qualify for SSDI will be eligible for Medicare coverage, but not until two years after the SSDI benefits start.

You might consider hiring an attorney who specializes in SSDI. Generally you can receive a free consultation that will outline the legal services provided and what they can do for you. There is a fixed fee for this service that is limited to no more than two months of SSDI payments.

We should also note that some employers provide and/or carry disability insurance policies for their employees. This can be short-term and/or long-term disability coverage. If this is the case, you may want to speak to HR about what options are available to you in the event that your disease makes it impossible for you to continue working.



Social Security Disability Insurance

Indirect costs

Indirect costs of care can add up as well, especially if your specialized care is not close to home. The American Cancer Society has a travel assistance program, and the Hope Lodge Program provides low cost lodging located near some major medical centers. Many hospitals have lists of hotels near them that offer hospital rates to patients and families—ask for more information from the hospital’s information services or your referring physician. See earlier chapters and the resource section on other community and medical center programs that are complimentary for cancer patients and that can provide much needed supportive care while managing your cancer care.



NET Patient and General Cancer Organizations

Final thoughts for the road....

Though your journey with neuroendocrine cancer will be unique to you, we hope that reading this guide has made it clear that you are not alone.

We know from experience that it helps to be connected with others who have traversed similar terrain. Consider what you have read to be a trail map or travel guide so that when you come to a particular place, you will more likely recognize where you are and how you might proceed.

Best wishes on your journey!



RESOURCES

There are many resources available for patients to learn about NETs from trusted sources, which we identify here. We have also included more general cancer resources and information about support that is available. Some resources are grouped by specific topics referenced in the text.

Check the Healing NET Foundation website for regular updates to this list:
thehealingnet.org/patient-resources

NET 101: RESOURCES FOR THE NEWLY DIAGNOSED

Carcinoid Cancer Foundation provides Newly Diagnosed the Basics, which leads also to Newly Diagnosed 2:

carcinoid.org/for-patients/diagnosis/newly-diagnosed-the-basics/

NET Research Foundation netrf.org/for-patients/newly-diagnosed/

National Institutes of Health (NIH) rarediseases.info.nih.gov/diseases/13445/neuroendocrine-tumor

LACNETS lacnets.org/newlydiagnosed

NorCal Carcinet norcalcarcinet.org/newly-diagnosed

Neuroendocrine Cancer Awareness Network will send an information packet to patients and families upon request netcancerawareness.org

MD Anderson 9 Things to Know about Neuroendocrine Tumors bit.ly/3mb7X3H

Living with NETs has a helpful glossary of terms, see: livingwithnets.com/en-us/glossary/

ORGANIZATIONS AND GROUPS THAT PROVIDE INFORMATION AND/OR SUPPORT

Note: Many of these sites also post videos of experts explaining various topics. Some NET organizations hold patient conferences, and usually those presentations can be found online. Knowledge of this disease is evolving quickly so you may want to focus on the most recent material.

Neuroendocrine Cancer Organizations (Chapter 2)

The Healing Net Foundation thehealingnet.org

Neuroendocrine Cancer Awareness Network (NCAN) netcancerawareness.org/patient-info/

Neuroendocrine Tumor Research Foundation (NETRF) NETRF.org

Carcinoid Cancer Foundation carcinoid.org

North American Neuroendocrine Tumor Society (NANETS) nanets.net/resources/patient-resources

NCCN Guidelines for Patients, Neuroendocrine Tumors

nccn.org/patients/guidelines/content/PDF/neuroendocrine-patient.pdf

Los Angeles Carcinoid Neuroendocrine Tumor Society (LACNETS) lacnets.org

Northern California CarciNET Community norcalcarcinet.org

The Pheo Para Alliance pheopara.org/about/the-alliance

AMEN American Multiple Endocrine Neoplasia Support amensupport.org/

Amend USA Organization for MEN1 and 2 patients in US amend.org.uk/patients/usa/

Neuroendocrine Cancer UK neuroendocrinecancer.org.uk

Canadian Neuroendocrine Tumor Society cnets.ca/

International Neuroendocrine Cancer Alliance (INCA) incalliance.org

Ronny Allan–Living with Neuroendocrine Cancer is an informational patient blog that is searchable by topic ronnyallan.net

Inter Science Institute offers a free PDF download of *Neuroendocrine Tumors: A Comprehensive Guide to Diagnosis and Management*, which has detailed information on biomarkers. bit.ly/372BsQP

Local Support Groups (Chapter 2)

Because of the rarity of this cancer, local support groups can be hard to find. Try these sites to look for a group near you. You can also find guidance to start your own group.

NETRF allows you to search the category “patient group” in their database:

netrf.org/for-patients/neuroendocrine-tumor-doctor-database/

CCF has a directory: carcinoid.org/resources/support-groups/

NCAN lists their chapters: netcancerawareness.org/chapters/

General Cancer Organizations (Chapter 2)

Cancer Support Community (merger of Gilda’s Club Worldwide and The Wellness Community) offers wellness programs, groups and free individual counseling for cancer patients and immediate family members: cancersupportcommunity.org

American Society of Clinical Oncology cancer.net

National Coalition for Cancer Survivorship offers resources for taking care of yourself as well as advocating for yourself: canceradvocacy.org

Livestrong Foundation provides tools and resources to support you as a cancer survivor or caregiver: livestrong.org

American Cancer Society cancer.org

SPECIFIC RESOURCES BY TOPIC

Communication and Organizational Tools (Chapter 2)

NET Vitals is a patient-physician communication tool created by LACNETS to help you track essential NET information: lacnets.org/netvitals

Carcinoid NETs Health Storylines, an app by Carcinoid Cancer Foundation, allows you to track symptoms, nutrition, moods, medication and more: healthstorylines.com/blog/?page_id=476

LivingWith is an app for storing information from doctor's visits and for communicating with loved ones: thisislivingwithcancer.com/living-with-app

Abridge is an app to record the conversation at medical appointments: abridge.com

Emergency bracelets: The Road-ID contains an access code to current medical records you have uploaded to the cloud. Emergency personnel can quickly access your medical records and respond appropriately: roadid.com/ Lauren's Hope has decorative styles to be engraved with your emergency information: LaurensHope.com

Lotsa Helping Hands is a tool to coordinate meals and organize other help: lotsahelpinghands.com

CaringBridge is a communication tool for connecting with the people who care about you and want to help: caringbridge.org

Advance Care Planning (Chapter 3)

LACNETS "What Matters Most" webinar with palliative care clinician, author, poet, educator Redwing Keyssar, RN [youtube.com/watch?v=ef4GurXrOC8&t=1s](https://www.youtube.com/watch?v=ef4GurXrOC8&t=1s)

NETRF Advance Care Planning netrf.org/for-patients/living-with-nets/coronavirus-disease-covid-19-outbreak/advance-care-planning

PREPARE for your care – advice on completing advance health care directives: prepareforyourcare.org/welcome

National Comprehensive Cancer Network Advance Directives
nccn.org/patients/resources/life_with_cancer/advance_directives.aspx

Carcinoid Syndrome and Other Symptom Management (Chapter 4)

National Organization for Rare Disorders (NORD) rarediseases.org/rare-diseases/carcinoid-syndrome/

Carcinoid Cancer Foundation www.carcinoidsyndrome.org/

Mayo Clinic mayoclinic.org/diseases-conditions/carcinoid-syndrome/symptoms-causes/syc-20370666

National Center for Biotechnology Information Carcinoid Syndrome article bit.ly/3qMb6ui

The pharmaceutical companies with medications for NETs (Sandostatin, Somatuline, Xermelo, Bynfezia) often provide excellent information about carcinoid syndrome on the medication websites.

Giving and Receiving Care (Chapter 6)

LACNETS has a NET Caregiver Support Group bit.ly/NETcaregivergroup and resources for caregivers lacnets.org/caregivers

Ring Theory “How not to say the wrong thing” by Susan Silk and Barry Goldman latimes.com/opinion/op-ed/la-xpm-2013-apr-07-la-oe-0407-silk-ring-theory-20130407-story.html

Share The Care™ is an approach for caregivers to build a powerful caregiving team sharethecare.org

CancerCare has a resource for coping with cancer on your own media.cancercare.org/publications/original/265-fs_on_your_own.pdf

Help for Cancer Caregivers has a description of respite care bit.ly/3n4v1IT

100 Acts of Love shares many ways to help someone living with cancer 100actsoflove.com and 100actsoflove.com

American Cancer Society provides caregiver resources, including a downloadable guide cancer.org/treatment/caregivers

Legal, Insurance and Financial Challenges (Chapter 7)

Triage Cancer provides education on practical and legal issues impacting cancer patients and their caregivers at triagecancer.org. See their Checklist to Minimize Financial Toxicity triagecancer.org/Checklist-FinancialToxicity. See their listing of state by state regulations for the health insurance industry triagecancer.org/health-insurance-state-laws. For cancer resources by state, see triagecancer.org/cancer-resources-and-educational-information/stateresources

National Cancer Institute has a web page on Financial Toxicity (Financial Distress) and Cancer Treatment www.cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-pdq#_273

Livestrong provides a summary of results from a 2015 survey Financial Impact of Cancer on Survivors www.livestrong.org/sites/default/files/what-we-do/reports/ls_survey_financial_concerns.pdf

Laurie Todd is a cancer survivor who has made it her business to help those with cancer appeal denials of insurance coverage. Examples of appeal letters and links to her books can be found on her website theinsurancewarrior.com

Patient Advocate Foundation provides case management services and financial aid to Americans with chronic, life threatening and debilitating illnesses patientadvocate.org

Cancer Legal Resource Center, a program of the Disability Rights Legal Center, provides free cancer-related legal information and a Patient Legal Handbook thedrlc.org/cancer

Medicare (Chapter 7)

The Official U.S. Government Site for Medicare is a comprehensive site for the Medicare program and all things relating to coverage, plans and regulations. medicare.gov
This page explains the supplemental insurance or **Medigap** coverage: medicare.gov/supplements-other-insurance/when-can-i-buy-medigap

The Medicare Rights Center is a national, non-profit consumer service organization that works to ensure access to affordable health care for older adults and people with disabilities: medicarerights.org/about

Medicare Interactive is a service of the Medicare Rights Center and is a free and independent online reference tool designed to help people and HCPs navigate the complex world of health insurance: medicareinteractive.org/

Check out their page on programs to offset Medicare costs for low-income individuals medicareinteractive.org/get-answers/cost-saving-programs-for-people-with-medicare/overview-of-cost-saving-programs/glossary-of-programs-that-help-pay-medicare-costs-for-people-with-limited-incomes

The State Health Insurance Assistance Program will help all Medicare eligible individuals determine what coverage is best for you: shiptacenter.org

The Center for Medicare Advocacy is a national nonprofit law organization that helps older people and people with disabilities obtain access to Medicare and quality health care: medicareadvocacy.org

The Centers for Medicare & Medicaid Services created this Government Glossary of Health Coverage and Medical Terms (OMB Control Numbers 1545-2229, 1210-0147, and 0938-1146) cms.gov/ccio/resources/files/downloads/uniform-glossary-final.pdf

Yale Insights “Choosing the Wrong Health Insurance Could Kill You” by Jason Abaluck: bit.ly/2W0YaST Download the full study at nber.org/papers/w27578

Social Security Disability Insurance (Chapter 7)

NOLO sells an excellent resource with guidance on applying for Social Security Disability, which you may also be able to find at your local library: store.nolo.com/products/nolos-guide-to-social-security-disability-qss.html

Triage Cancer has a Quick Guide to Navigating SSDI: triagecancer.org/quickguide-ssdiandssi

Social Security has updated and comprehensive information on government disability benefits ssa.gov/benefits/disability/

Medication Costs (Chapter 7)

NeedyMeds is a free online resource to help people afford their medications and health care costs: needymeds.org

Goodrx is a pharmacy discount program that may reduce the costs of your medications lower than what your insurance would charge: goodrx.com/

The Lois Merrill Foundation provides patients in financial need with medical expense assistance: thelmf.com/

Patient Assistance programs offered by many pharmaceutical companies can help offset costs. Search by entering the drug company name or drug name **and** “patient assistance program.” See also thehealingnet.org/paying-for-meds



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