



CANCERcare®

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fact sheet

AFTER A NEUROENDOCRINE TUMORS DIAGNOSIS: QUESTIONS TO ASK YOUR DOCTOR

A diagnosis of neuroendocrine tumors (NETs) can leave you and your loved ones feeling uncertain, anxious and overwhelmed. As your health care team talks about your diagnosis and treatment, ask questions about anything you don't understand. Good communication with your doctor will help improve the quality of the care you receive. It's a good idea to bring a list of questions to the appointment and write down the doctor's responses. In addition, if possible, bring someone with you to any appointment; another set of ears can help reduce confusion.

HERE IS A LIST OF QUESTIONS THAT YOU MAY WANT TO ASK YOUR HEALTH CARE TEAM

Since I've been diagnosed, I've been overwhelmed. How can I better cope with my diagnosis?

A cancer diagnosis turns a person's world upside down emotionally and physically. Your team of doctors, nurses and social workers are valuable sources of support as you cope with a cancer diagnosis. Oncology social workers are licensed professionals who counsel people affected by cancer, providing emotional support and helping people access practical assistance. CancerCare's oncology social workers provide individual counseling, support groups and locate services face-to-face, online or on the telephone, free of charge. To learn more, visit www.cancercares.org or call 800-813-HOPE (4673).

What type of NETs do I have and where is the tumor located? NETs are a rare type of cancer that most commonly occur in the pancreas, lung or stomach. Cancer occurs when the cells found in these areas begin to change and grow uncontrollably, forming a tumor (also called a nodule), which can be either cancerous or benign.

What stage is my tumor? A tumor's stage refers to its size and extent of spread in the body—e.g., whether it has spread to lymph nodes or other organs. Cancer that has spread to other organs is called metastatic cancer. A cancer's stage is often denoted by a Roman numeral (I, II, III or IV). The higher the numeral, the more the cancer has spread within the body.

Should I see a doctor that specializes in NETs? It is common and even encouraged for patients to request second opinions from a specialist. To find a NETs specialist, ask your primary care doctor or oncologist to recommend one, or contact a nearby cancer center. For information about hospitals, cancer treatment facilities, and surgical centers contact:

- The American Society of Clinical Oncology's website, Cancer. Net, offers a "Find an Oncologist" database that allows you to search by many different criteria, including area of specialty, board certification, and location.
- The National Cancer Institute (www.cancer.gov or 800-4-CANCER) publishes a list of NCI Designated Cancer Centers.

A representative from your health insurance company may also assist

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you in seeking a doctor whose specialty is NETs. Speaking with your insurance representative would also help you understand your coverage and learn whether or not you would be allowed to go out of network to see a specialist.

What is my recommended treatment plan?

Depending on the information that your health care team has learned about your tumor, your treatment options may include surgery, radiation therapy, targeted therapy and chemotherapy.

What side effects can I experience throughout my treatment plan?

Keep in mind that side effects can vary from person to person, and can be treated by your health care team. A key to managing side effects is to be aware of them and communicate with your health care team when they arise. Report them right away—don't wait for your next appointment. Your health care team can help you cope with side effects of uterine cancer treatment. To help you get relief from side effects, your doctors and nurses need to know specific details about your symptoms. By keeping a side effect journal and bringing it with you to medical appointments, you can have this kind of information ready to share with them. Some of the things you may want to write down in your journal include:

- How long a side effect lasts
- The date and time a side effect occurs
- What impact the side effect has on your daily activities. For example—does pain keep you from sleeping?
- How strong the side effect is. For example—if you experience pain, how strong is it on a scale from 0 to 10, where 0 equals no pain and 10 is the worst pain possible?

CancerCare® Can Help

Founded in 1944, CancerCare is the leading national organization providing free support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by professional oncology social workers and world-leading cancer experts.

To learn more, visit www.cancercares.org or call **800-813-HOPE (4673)**.

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Read CancerCare's fact sheet titled, "The Value of Assertiveness When Talking to Your Doctor" for more information on communicating with your health care team.

Should I change my diet? It's important to talk with your health care team, both during and after treatment, about your diet. A NETs diagnosis can affect the pancreas, which helps digestion, and the stomach. Find out if your doctor has a registered dietitian (RD) on staff or can recommend one. RDs are experts in diet and nutrition and can advise you about eating right.

Is there a clinical trial I can participate in? If so, will it be covered by my insurance? Clinical trials are the standard by which we measure the worth of new treatments and the quality of life of patients as they receive those treatments. For this reason, doctors and researchers urge people with cancer to take part in clinical trials. Read CancerCare's "Clinical Trials: What You Need to Know" fact sheet to learn more information on clinical trials.



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