

Diagnosed with a Neuroendocrine Tumor?

6 Questions to Ask Your Doctor



Getting a cancer diagnosis is often overwhelming and confusing, so knowing the right questions to ask your doctor is important. Having a neuroendocrine tumor or NET can be very different from other cancers. Knowing the basic facts about your disease, can help you better understand what to expect going forward and what treatment options might be right for you.

1

WHAT IS A NEUROENDOCRINE TUMOR (NET) AND WHAT TYPE DO I HAVE?

NETs develop from hormone producing cells, which are found in many different parts of the body. Common sites for NETs include the gastrointestinal (GI) tract, lungs and pancreas, but they can form anywhere in the body. NETs are typically classified by the part of your body in which the primary tumor is located. The primary tumor location may have an impact on next steps.

2

DOES MY TUMOR MAKE HORMONES?

If the answer is yes, you may have carcinoid syndrome, which can include one or more symptoms such as flushing, diarrhea, shortness of breath, weight loss, and fatigue. Carcinoid syndrome requires treatment, usually with long-acting monthly injections called somatostatin analogues to help manage symptoms.

3

HOW SERIOUS IS MY CANCER - WHAT IS THE STAGE AND GRADE?

How serious your cancer is can be determined using a variety of factors, including stage (if it is in one spot or has spread - scale of 1-4), grade (how aggressive it is, measured by how rapidly the cells are dividing - Ki67 score), what the tumor cells look like, how much tumor there is (tumor burden) and your overall health. These criteria will have a strong impact on next steps and prognosis. Generally, the higher the stage and grade, the more serious and complex your disease. However, with proper management, it is possible for NET patients, even those whose cancer has spread, to live long lives.

4

WHAT ARE MY TREATMENT OPTIONS?

Treatments vary from person to person and include surgery (for both removal and “debulking” or reducing tumor burden), somatostatin analogues for managing carcinoid syndrome, oral medications to slow cancer growth, different types of embolization for tumors that have spread to the liver, and nuclear medicine. Talk to your doctor/team of doctors about what is recommended for you, and when.

5

HOW WILL I BE FOLLOWED?

Follow up and monitoring of your disease can include lab tests and blood work (the 24-hour urine test called 5-HIAA or the plasma version of that test), and imaging with nuclear agents. How often and which types of tests you have depend upon where you are with your disease, and often include follow up after treatments to determine the effectiveness of the treatment.

6

WHAT IS MY PROGNOSIS AND HOW WILL NETS AFFECT MY LIFE?

Prognosis and management of NETs differs from person to person, depending on the site, stage, grade and burden of your disease; whether your tumor can be removed surgically; and whether you are symptomatic, or have any other health issues. When properly managed, many diagnosed with NETs live with the disease as a chronic condition for years. Diet and lifestyle choices can often help you feel better. It is very important to work with doctors who are NET experts, so you have access to the latest research and most sophisticated tools for management.

Get information



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Talk to your doctor with your family and/or caregiver – make sure you all understand these critical factors, which may affect how your disease is managed.

If you don't suspect it, you can't detect it!
For more information, visit www.carcinoid.org