A diagnosis of neuroendocrine tumors (NETs) can leave you and your loved ones feeling uncertain, anxious and overwhelmed. There are important treatment decisions to make, emotional concerns to manage, and insurance and financial paperwork to organize, among other practical concerns.

It is helpful to keep in mind that there are many sources of information and support for people coping with NETs. By learning about this diagnosis and its treatment options, communicating with your health care team, and surrounding yourself with a support network, you will be better able to manage NETs and experience a better quality of life.

UNDERSTANDING YOUR DIAGNOSIS AND TREATMENT PLAN

NETs occurs when the cells most commonly in the lung, stomach or pancreas begin to change and grow uncontrollably, forming a tumor (also called a nodule), which can be either cancerous or benign.

There are a wide range of treatments for NETs, including surgery, radiation therapy, targeted therapy and chemotherapy. If treatment is necessary, ask your health care team to recommend reliable publications and websites to learn more. Knowing what to expect can help you feel more in control.

THE IMPORTANCE OF COMMUNICATING WITH YOUR HEALTH CARE TEAM

Because NETs is a complex condition with complex treatment options, good communication between you and your health care team is key. Your oncologist, nurses, and other members of your health care team work together to treat your NETs. When your health care team talks about your diagnosis and treatment, ask questions about anything you don’t understand. As you start getting more information about your diagnosis, you will learn that there are many effective treatment options and many places you can turn to for help and hope. Since medical appointments are the main time you will interact with your team, being as prepared as possible for these visits is important. It will help ensure that you understand your diagnosis and treatment, get answers to your questions, and feel more satisfied with your overall care. Read CancerCare’s fact sheet, “Doctor, Can We Talk?: Tips for Communicating With Your Health Care Team,” to learn how you can communicate more effectively with your health care team.

FINDING RESOURCES

While NETs can present many challenges, keep in mind that you do not need to cope with this diagnosis on your own. Your friends and family are important sources of strength and support. There are also many local and national support services available to assist you.

Financial Assistance. There are many organizations that provide help with medical billing, insurance coverage, and reimbursement issues. There is also financial assistance...
available to help people who cannot afford the cost of their medications. A good place to start your research is the website of the Partnership for Prescription Assistance (www.pparx.org).

CancerCare’s fact sheet, “Sources of Financial Assistance,” provides more information about seeking financial help. Another resource is CancerCare’s A Helping Hand (www.cancercare.org/helpinghand). This is a searchable, online database of financial and practical assistance available for people with cancer. This comprehensive online tool features up-to-date contact information and descriptions for hundreds of national and regional organizations offering financial help to people with cancer. You can search by diagnosis, zip code and type of assistance.

Benefits and entitlements. Local and county government agencies can give you information on Social Security, state disability, Medicaid, income maintenance, the Low Income Heating Energy Assistance Program (LIHEAP), and food stamps. Check your local phone directory for listings.

Housing/Lodging. The Hope Lodge of the American Cancer Society, the National Association of Hospital Hospitality Houses (www.nahhh.org), and other organizations provide temporary lodging for families of a patient who needs to travel far from their home for treatment. Joe’s House is a nonprofit organization that offers an online database with lodging information near cancer treatment centers across the U.S. To learn more, visit www.joeshouse.org.

KNOW YOUR INSURANCE COVERAGE
Understand ahead of time which treatments and medical services your insurance covers, and whether you are still responsible for any out-of-pocket expenses. A good first step is to contact your insurance company using the telephone number found on the back of your insurance card. For more information about insurance, read CancerCare’s fact sheets titled, “Understanding Your Insurance Coverage” and “Coping with Cancer When You’re Uninsured.”

GETTING EMOTIONAL SUPPORT
Adjusting to and finding ways to cope with an NETs diagnosis is an important part of healing, along with treatment. There are many organizations, such as CancerCare, that provide support services to help people affected by cancer. Individual counseling is available to help you learn ways to cope with the emotions and challenges raised by your diagnosis. Support groups can connect you with other patients in a safe, supportive environment. Cancer affects the whole person and their loved ones, so it’s important to create a support network as part of managing your care.

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.cancercare.org or call 800-813-HOPE (4673).
Facebook: facebook.com/cancercare | Twitter: @cancercare