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10 TIPS TO LIVING WELL WITH
Neuroendocrine &
Carcinoid Tumors (NETs)

The journey through a neuroendocrine and carcinoid tumor diagnosis is different for everyone. There is no single roadmap. These tips come from other survivors. Whether you are a patient or a caregiver, we hope that they will help make your journey easier.

1. Take one step at a time, and make one decision at a time.

Life with a neuroendocrine or carcinoid tumor diagnosis can feel overwhelming. Yet, with small steps you can find your best path. Before making major decisions, talk with a variety of medical experts, patient navigators, and neuroendocrine and carcinoid tumor advocates. Don't trust everything you read online. Ask all of your questions. Collect the information and support you need to make good financial, medical, and personal decisions.

2. Find a treatment team you trust. Your team might include a gastroenterologist, oncologist, endocrinologist, surgeon, pulmonologist, radiologist, nuclear medicine specialist, pathologist, cardiologist, nurses, social workers, nutritionist, and patient advocates. Trust comes from being able to talk openly with your team and believing they can help. Try to get a second opinion. Treat this like an interview to find the best experts for the job. Your team should help you care for your mind, body, and spirit.

3. Use a notebook to keep track of your symptoms, answers to questions, and next steps. Ask someone to help you keep notes.

Look back at your notebook to help you remember and track how you're doing over time.

4. Accept help. Day-to-day life and tasks can become harder. Ask others for the help you want and need. Often, your friends and family will feel good offering assistance. An online scheduler like www.MyLifeLine.org can help you and your loved ones stay organized and informed.

5. Reach out to other neuroendocrine and carcinoid tumor survivors. It's comforting to talk with others who understand what you're going through. You and your loved ones don't have to feel lonely, helpless, or hopeless. You can connect with others through the Internet or a local support group.

6. Seek support from a patient advocate. A trained advocate can help you navigate through many parts of the cancer journey. They can help manage insurance issues and find you resources. They can also help with legal documents such as your will, medical directives, and estate plans. Many cancer centers offer, or can refer you to, a skilled advocate or patient navigator.

- 7. Learn to relax and find a new perspective.** A neuroendocrine and carcinoid tumor diagnosis is life changing. Be aware of your feelings and how you handle them. Calm yourself with deep breathing, journaling, exercise, or creative activities. If you feel worried or depressed, try talking with a social worker or therapist. You can learn to manage your feelings and find a sense of calm. Take time to think about your life goals and self-image. Explore what's important to you and what makes you feel happy. Focus your energy on things that improve your well-being.
- 8. Find ways to feel in charge of your life.** At times you may feel frustrated by changes to your work, school, and family life. Take action. Come up with a plan with your medical team that gives you as much control as possible over your treatment and care.
- 9. Focus on nutrition and exercise.** Every small step you take to eat better and get more exercise helps your body. Exercise can lift your spirits, boost your energy, and reduce stress. Even when you feel tired, you can set reachable goals for healthy eating and exercise (example: a 10-minute walk).
- 10. Remember that hope is possible.** It may help to focus on family connections, cultural customs, and spiritual beliefs. If a cure is unlikely, hope can still make each new day better in some way. Plan to do something that makes you smile. Accept that some days will be better than others, but you can continue to enjoy the small, special moments.

CancerSupportCommunity.org/NETs has more information and tips on coping.

RECOMMENDED RESOURCES

American Society of Clinical Oncology

888-651-3038
www.cancer.net

CancerCare

800-813-4673
www.cancercares.org

Cancer.gov/ClinicalTrials

Carcinoid Cancer Foundation

888-722-3132
www.carcinoid.org

MyLifeLine.org

888-234-2468
www.MyLifeLine.org
Inform loved ones and schedule their help.

National Cancer Institute

800-422-6237
www.cancer.gov

Neuroendocrine Tumor Research Foundation

617-946-1780
https://netrf.org

North American Neuroendocrine Tumor Society

650-762-6387
https://nanets.net
NETs treatment guidelines & clinical trials.

Patient Advocate Foundation

800-532-5274
www.patientadvocate.org

CANCER SUPPORT COMMUNITY RESOURCES

The Cancer Support Community's (CSC) resources and programs are available free of charge. Call 888-793-9355 or visit www.CancerSupportCommunity.org for more info.

Cancer Support Helpline®

**CANCER SUPPORT
HELPLINE
888-793-9355** Have questions, concerns or looking for resources?

Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon - Fri 9am - 9pm ET.

Frankly Speaking about Cancer®

**FRANKLY
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ABOUT CANCER** Trusted information for cancer patients and their loved ones

is available through publications, online, and in-person programs.

MyLifeLine

CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at www.MyLifeLine.org.

Open to Options®



Need help making a cancer treatment decision? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Services at Local CSCs and Gilda's Clubs

With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you.

Cancer Experience Registry®



Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

Grassroots Network

Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate.

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