

## 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](http://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/](http://carcinoid.org/for-patients/diagnosis/newly-diagnosed-the-basics/)

**NET Research Foundation** [netrf.org/for-patients/newly-diagnosed/](http://netrf.org/for-patients/newly-diagnosed/)

**National Institutes of Health (NIH)** [rarediseases.info.nih.gov/diseases/13445/neuroendocrine-tumor](http://rarediseases.info.nih.gov/diseases/13445/neuroendocrine-tumor)

**LACNETS** [lacnets.org/newlydiagnosed](http://lacnets.org/newlydiagnosed)

**NorCal Carcinet** [norcalcarcinet.org/newly-diagnosed](http://norcalcarcinet.org/newly-diagnosed)

**Neuroendocrine Cancer Awareness Network** will send an information packet to patients and families upon request [netcancerawareness.org](http://netcancerawareness.org)

**MD Anderson 9 Things to Know about Neuroendocrine Tumors** [bit.ly/3mb7X3H](http://bit.ly/3mb7X3H)

**Living with NETs** has a helpful glossary of terms, see: [livingwithnets.com/en-us/glossary/](http://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](http://thehealingnet.org)

**Neuroendocrine Cancer Awareness Network (NCAN)** [netcancerawareness.org/patient-info/](http://netcancerawareness.org/patient-info/)

**Neuroendocrine Tumor Research Foundation (NETRF)** [NETRF.org](http://NETRF.org)

**Carcinoid Cancer Foundation** [carcinoid.org](http://carcinoid.org)

**North American Neuroendocrine Tumor Society (NANETS)** [nanets.net/resources/patient-resources](http://nanets.net/resources/patient-resources)

**NCCN Guidelines for Patients, Neuroendocrine Tumors**

[nccn.org/patients/guidelines/content/PDF/neuroendocrine-patient.pdf](http://nccn.org/patients/guidelines/content/PDF/neuroendocrine-patient.pdf)

**Los Angeles Carcinoid Neuroendocrine Tumor Society (LACNETS)** [lacnets.org](http://lacnets.org)

**Northern California CarciNET Community** [norcalcarcinet.org](http://norcalcarcinet.org)

**The Pheo Para Alliance** [pheopara.org/about/the-alliance](http://pheopara.org/about/the-alliance)

**AMEN American Multiple Endocrine Neoplasia Support** [amensupport.org/](http://amensupport.org/)

**Amend USA Organization for MEN1 and 2 patients in US** [amend.org.uk/patients/usa/](http://amend.org.uk/patients/usa/)

**Neuroendocrine Cancer UK** [neuroendocrinecancer.org.uk](http://neuroendocrinecancer.org.uk)

**Canadian Neuroendocrine Tumor Society** [cnets.ca/](http://cnets.ca/)

**International Neuroendocrine Cancer Alliance (INCA)** [incalliance.org](http://incalliance.org)

**Ronny Allan–Living with Neuroendocrine Cancer** is an informational patient blog that is searchable by topic [ronnyallan.net](http://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](http://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/](http://netrf.org/for-patients/neuroendocrine-tumor-doctor-database/)

**CCF** has a directory: [carcinoid.org/resources/support-groups/](http://carcinoid.org/resources/support-groups/)

**NCAN** lists their chapters: [netcancerawareness.org/chapters/](http://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](http://cancersupportcommunity.org)

**American Society of Clinical Oncology** [cancer.net](http://cancer.net)

**National Coalition for Cancer Survivorship** offers resources for taking care of yourself as well as advocating for yourself: [canceradvocacy.org](http://canceradvocacy.org)

**Livestrong Foundation** provides tools and resources to support you as a cancer survivor or caregiver: [livestrong.org](http://livestrong.org)

**American Cancer Society** [cancer.org](http://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](http://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](http://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](http://thisislivingwithcancer.com/living-with-app)

**Abridge** is an app to record the conversation at medical appointments: [abridge.com](http://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/](http://roadid.com/) Lauren's Hope has decorative styles to be engraved with your emergency information: [LaurensHope.com](http://LaurensHope.com)

**Lotsa Helping Hands** is a tool to coordinate meals and organize other help: [lotsahelpinghands.com](http://lotsahelpinghands.com)

**CaringBridge** is a communication tool for connecting with the people who care about you and want to help: [caringbridge.org](http://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](http://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](http://prepareforyourcare.org/welcome)

**National Comprehensive Cancer Network Advance Directives**  
[nccn.org/patients/resources/life\\_with\\_cancer/advance\\_directives.aspx](http://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/](http://rarediseases.org/rare-diseases/carcinoid-syndrome/)

**Carcinoid Cancer Foundation** [www.carcinoidsyndrome.org/](http://www.carcinoidsyndrome.org/)

**Mayo Clinic** [mayoclinic.org/diseases-conditions/carcinoid-syndrome/symptoms-causes/syc-20370666](http://mayoclinic.org/diseases-conditions/carcinoid-syndrome/symptoms-causes/syc-20370666)

**National Center for Biotechnology Information** Carcinoid Syndrome article [bit.ly/3qMb6ui](https://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](http://bit.ly/NETcaregivergroup) and resources for caregivers [lacnets.org/caregivers](http://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](http://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](http://sharethecare.org)

**CancerCare** has a resource for coping with cancer on your own [media.cancercare.org/publications/original/265-fs\\_on\\_your\\_own.pdf](http://media.cancercare.org/publications/original/265-fs_on_your_own.pdf)

**Help for Cancer Caregivers** has a description of respite care [bit.ly/3n4v11T](http://bit.ly/3n4v11T)

**100 Acts of Love** shares many ways to help someone living with cancer [100actsoflove.com](http://100actsoflove.com) and [100actsoflove.com](http://100actsoflove.com)

**American Cancer Society** provides caregiver resources, including a downloadable guide [cancer.org/treatment/caregivers](http://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](http://triagecancer.org). See their Checklist to Minimize Financial Toxicity [triagecancer.org/Checklist-FinancialToxicity](http://triagecancer.org/Checklist-FinancialToxicity). See their listing of state by state regulations for the health insurance industry [triagecancer.org/health-insurance-state-laws](http://triagecancer.org/health-insurance-state-laws). For cancer resources by state, see [triagecancer.org/cancer-resources-and-educational-information/stateresources](http://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](http://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](http://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](http://theinsurancewarrior.com)

**Patient Advocate Foundation** provides case management services and financial aid to Americans with chronic, life threatening and debilitating illnesses [patientadvocate.org](http://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](http://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](http://medicare.gov)  
This page explains the supplemental insurance or **Medigap** coverage: [medicare.gov/supplements-other-insurance/when-can-i-buy-medigap](http://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](http://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/](http://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](http://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](http://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](http://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](http://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](http://bit.ly/2W0YaST) Download the full study at [nber.org/papers/w27578](http://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](http://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](http://triagecancer.org/quickguide-ssdiandssi)

**Social Security** has updated and comprehensive information on government disability benefits [ssa.gov/benefits/disability/](http://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](http://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/](http://goodrx.com/)

**The Lois Merrill Foundation** provides patients in financial need with medical expense assistance: [thelmf.com/](http://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](http://thehealingnet.org/paying-for-meds)