ADULT: NATIONAL RESOURCES



Advocacy

- National Adult Protective Services Association
 - Promoting the dignity, health, safety and independence of adults with disabilities and the elderly, fighting to diminish discrimination, abuse, and neglect. Provides advocacy and resources. http://www.napsa-now.org/;
 Local phone numbers
- Disability Rights Advocates
 - DRA has 13 lawyers, many of whom have disabilities. Its lawyers work in multiple practice areas such as education, employment, emergency planning, health care, access to public and private facilities and services, technology, telecommunications, transportation and veterans benefits. http://www.dralegal.org/; (510) 665-8644
- Patient Advocate Foundation
 - Education, resources, referrals, consultation, financial assistance, active advocacy from case managers, doctors, and attorneys to address access to medical care, medical debt, and job retention issues related to your diagnosis. Webchat, email, and/or telephone correspondence http://www.patientadvocate.org/ 1 (800) 532-5274
- National Alliance on Mental Illness (NAMI)
 - Advocacy topics and referral include legal help, public policy, health care reform, criminal justice, access to medications, housing, employment, and an Advocacy Action Center where patrons can take the opportunity to advocate.
 - http://www.nami.org/template.cfm?section=About_Public_Policy
 - Information Helpline: 1 (800) 950-6264
 - Andrew Sperling, Director of Legislative Affairs, andrew@nami.org
 - Sita Diehl, Director of State Policy & Advocacy, <u>sdiehl@nami.org</u>
 - Jean Moore, Manager of Military & Veterans Policy and Support, jeanmoore@nami.org

Cancer

- American Cancer Society- Education, prevention, support, and research on dozens of cancer types http://www.cancer.org (800) 227-2345
- National Comprehensive Cancer Network- The National Comprehensive Cancer Network® (NCCN®), a not-for-profit alliance of 23 of the world's leading cancer centers devoted to patient care, research, and education, is dedicated to improving the quality, effectiveness, and efficiency of cancer care so that patients can live better lives. Through the leadership and expertise of clinical professionals at NCCN Member Institutions http://www.nccn.org/about/default.aspx

- Mayo Clinic "Living With Cancer" Newsletter Sign-uphttps://newslettersignup.mayoclinic.com/?fn=204
- CancerCare- Counseling, Support Groups, Resources, Financial Assistance-Meant to support patients, family members and loved ones, and healthcare professionals http://www.cancercare.org/ (800) 813-4673
- Cancer Hope Network- Trained cancer survivors conduct a one-on-one support program that encourages patients to continue chemotherapy, immunotherapy, radiation, and surgery, even in the face of adverse side effects www.cancerhopenetwork.org; 1 (800) 552-4366
- Look Good...Feel Better- Website that gives beauty tips and tricks for cancer patients during and after intensive treatments- www.lookgoodfeelbetter.org
- Breast Cancer
 - Susan G. Komen Foundation- http://ww5.komen.org/
 - National Breast Cancer Foundation-http://www.nationalbreastcancer.org/; Beyond The Shock- NBCF online guide to understanding breast cancer for women just diagnosed, family members, and medical professionals. Available as a website or app, http://beyondtheshock.com
 - Air Charity Network

Providing air transportation for cancer patients.

website: http://www.aircharitynetwork.org/

phone: (877) 621-7177

CancerCare

Provides transportation to and from their cancer treatments.

website: http://www.cancercare.org/ phone: 1-800-813-HOPE (4673)

Corporate Angel Network

Provides air travel to treatment centers for cancer patients.

website: www.corpangelnetwork.org

phone: (866) 328-1313

Elder Help

Helping the population of growing seniors with financial assistance, transportation, and other support services.

website: http://www.elderhelpofsandiego.org/

phone: (619) 284-9281

National Patient Travel Center

Providing patients with air travel to treatment centers.

website: http://www.patienttravel.org/

phone: (800) 296-1217

Road to Recovery (American Cancer Society)

Helping patients get to and from treatment centers.

website:

http://www.cancer.org/InYourArea/California/ProgramsandServices/patient-transportation

phone: (800) 227-2345

- Brain Tumors
 - American Brain Tumor Association http://www.abta.org/, (800) 866-2282
- Leukemia & Lymphoma
 - Leukemia & Lymphoma Society- Treatment, education, support, financial matters- http://www.lls.org/, 1 (800) 955-4572
 - Lymphoma Research Foundation- Education, advocacy, personalized support network, research, resources, referral- http://www.lymphoma.org;
 Questionnaire for support network match-ups http://www.lymphoma.org/site/apps/fc/form.asp?c=bkLTKaOQLmK8E&b=6292571
 - National Bone Marrow Transplant Link- Information, education, support for patients and caregivers- http://www.nbmtlink.org/;
- Ovarian Cancer
 - Ovarian Cancer National Alliance- Support, connection with patients and survivors, guidance, education, advocacy, resources, clinical trials, symptom journals- http://www.ovariancancer.org/ (202) 331-1332
 - National Ovarian Cancer Coalition- Raising awareness and promoting education, literature, new diagnosis info packets, tips on how to navigate through care- http://www.ovarian.org 1 (888) 682-7426
- Pancreatic Cancer
 - Pancreatic Cancer Action Network- Research, patient support, advocacy, treatment options, education- http://www.pancan.org/ Patient and Liaison Services (PALS), One-on-one support Mon-Fri 7am-5pm, (877) 272-6226
 - National Pancreatic Cancer Foundation- Early detection research, educational awareness, financial assistance, and online support groupshttp://pancreaticcancerfoundation.com (800) 859-6723

Skin Cancer

- The Skin Cancer Foundation- Prevention, early detection, treatment, physician locator, support, education, events, recommended products, healthy living- http://www.skincancer.org/
- American Melanoma Foundation- Facts, prevention, diagnosis, treatment, resources for support- http://www.melanomafoundation.org/index.html
- Aim at Melanoma- Education, research, advocacy, support, discussion boards- http://www.aimatmelanoma.org/en/index.html On-Call Nurse for patient, family and caregiver questions: (877) 246-2635

Thyroid Cancer

Thyroid Cancer Survivor's Association, Inc. (ThyCa)- Facts, types, stages, diagnosis, treatment, specialist locator, low-iodine diet and cookbook, support, education, resources, literature- http://www.thyca.org/newly-diagnosed/

• Chronic Health Issues

- Asthma, Allergies & Respiratory Conditions
 - The Asthma and Allergy Foundation of America- General information, education, everyday living tips, email correspondence with an allergist, advocacy, support, clinic locator- http://www.aafa.org/index_noflash.cfm
 - The American Lung Association- Education, everyday living tips, advocacy initiatives- http://www.lung.org
 - Food Allergy Research & Education- Research initiatives, education, tools, resources, support group directory, treatment & management, advocacy- http://www.foodallergy.org/

Diabetes

- American Diabetes Association- General information, facts, FAQs, research, support and networking, advocacy, management and treatment tips and tools, recipes, fitness, Diabetes 24/7 (online tool to help track and manage treatment plan)- http://www.diabetes.org/?loc=logo 1 (800) 342-2383 (Information & Community Support)
- Diabetic Connect- Lifestyle forum for individuals with diabetes. Popular topics include weight management, recipes, newly diagnosed, medications, complications- http://www.diabeticconnect.com/
- JDRF- Type 1 Diabetes support for any life stage, research info, advocacy, lifestyle tips, online support, downloadable toolkits, Care Kits for newly diagnosed (include sling bag, testing supplies, T1D literature)http://jdrf.org/; Online Support Team (Answer T1D related questions within 48 hours)- http://jdrf.org/get-support/online-diabetes-support-team/

Epilepsy

- Epilepsy Foundation- General information, resources, education, "e-Communities," lifestyle tips, newsletters, research, financial assistance, advocacy, community events- http://www.epilepsyfoundation.org/; Resource Hotline: 1 (800) 332-1000
- Epilepsy.com- Project initiative by The Epilepsy Therapy Project that gives lifestyle tips, support communities, information on the most recent therapies & medications, online seizure diary- http://www.epilepsy.com; http://www.facebook.com/epilepsytherapyproject
- Lundbeck- Organization that sponsors meeting the needs of those with central nervous system disorders, particularly epilepsy. Partners with the community and other foundations to bring art therapy (Studio e), Talk About It © community, events, research, sponsored clinical trials, and lifestyle tips- http://www.yourpartnerinepilepsy.com/
- The Epilepsy Advocate- Free magazine, community of caregivers and advocates providing education and lifestyle tips, resources. Sponsored by UCB Inc. Pharmaceuticals- http://www.epilepsyadvocate.com/

Heart Conditions

- American Heart Association- Prevention, education, resources for patients, caregivers, healthcare professionals on most recent, innovative, and effective treatments for heart conditionshttp://www.heart.org/HEARTORG/
 - HeartHub- Information portal for patients to access info on heart disease, heart attacks, risk factors, cholesterol, diabetes, arrhythmia, stroke, prevention, treatment, tools, BMI calculatorhttp://www.hearthub.org/
- Mended Hearts- Organization providing peer-to-peer support to heart patients, families, and caregivers through phone, online, and hospital visits. Supports education and resource connection as well as emotional support, lifestyle tips, prevention, and treatment of heart surgery and other serious heart conditions- http://mendedhearts.org/; support@mendedhearts.org; 1 (888) 432-7899
- World Heart Federation- Investment in education, research, prevention, and advocacy (i.e. Go Red for Women) to reduce heart disease and stroke occurrences around the world regardless of socio-economic status. Get resources, FAQs, new, and upcoming events- http://www.world-heart-federation.org/

• Pain Management (not cancer-related)

- American Chronic Pain Association- Lists of conditions from migraines to fibromyalgia to arthritis to chronic back pain, information on treatments and facts on medications, online and printable tools for pain management, lifestyle tips, publications & articles, resources- http://www.theacpa.org/
- PainACTION- Online database and tool to help individuals create a
 personalized plan to track, organize, and manage pain treatment to include
 lifestyle tips, tools for coping, daily tracker, and information for any
 condition that causes or exacerbates pain- http://www.painaction.com/
- American Headache Society Committee for Headache Education (ACHE)-Migraine education, awareness, treatment, prevention, research has useful handouts, toolkits, events, recent articles- http://www.achenet.org/
- National Headache Foundation- Head Wise Magazine, tools, FAQs, webinars, lifestyle times on managing chronic headacheshttp://www.headaches.org/
- Neurology Now- Online Magazine that covers a variety of neurological conditions such as migraines, epilepsy, Alzheimer's, and fibromyalgiahttp://journals.lww.com/neurologynow/pages/default.aspx
- Spine Health Online- Chronic back and neck pain information, treatment, prevention, pain management techniques, before/after surgery treatment & info, alternative medicine, resources, support- http://www.spine-health.com/
- Chronic Fatigue & Immune Deficiency Syndrome Association of America- Free literature, book lists, resources, advocacy, facts, FAQs for Chronic Fatigue Syndrome and Fibromyalgia- http://solvecfs.org/

Deaf & Hard of Hearing

- AbleData- Database of thousands of assistive technology products with reviews and general information, resources, literature on the latest assistive technology breakthroughs and interactive resources. Funded by the National Institute on Disability and Rehabilitation Research- http://www.abledata.com/; 1-800-227-0216
- American Speech-Language-Hearing Association- HELPLINE to help consumers with questions about speech & language pathology, audiology, deaf and hard of hearing conditions and treatments- http://www.asha.org/; (800) 638-8255
- National Association of the Deaf- Civil rights organization that provides advocacy, news, and education- http://www.nad.org/
- Hearing Loss Association of America- Information, community support, webinars, newsletters, free and low cost products, resources, advocacy, prevention and lifestyle tips- http://www.hearingloss.org/

Vision

- American Foundation for the Blind- Provides services to and acts as an information clearinghouse for people who are blind or visually impaired and their families, professionals, organizations, schools, and corporations http://www.afb.org/default.aspx Also hosts a family of websites:
 - VisionAwareTM- http://www.visionaware.org/
 - FamilyConnect®http://www.familyconnect.org/parentsitehome.asp
 - CareerConnect®http://www.afb.org/section.aspx?FolderID=2&SectionID=7
 - BrailleBug® (Intro to Braille for Kids)- http://braillebug.afb.org/
 - AccessWorld (Database of assistive technology)http://www.afb.org/aw/main.asp
- AbleData- Database of thousands of assistive technology products with reviews and general information, resources, literature on the latest assistive technology breakthroughs and interactive resources. Funded by the National Institute on Disability and Rehabilitation Research- http://www.abledata.com/; 1-800-227-0216
- National Federation for the Blind- Education, referrals, resources for independent living, working, education, and recreation, technology products such as mobile app and handheld reader, Jernigan Institute- https://nfb.org/

• Independent Living/Mobility

 National Council on Independent Living- Advocacy, toolkits, events, newsletter (The Advocacy Monitor) to support inclusion, civil rights, environmental considerations for all adults with disabilities- http://www.ncil.org/

• Mental/Emotional/Behavioral Health

- National Alliance on Mental Illness- Dedicated to education & awareness of mental illness, advocacy, education, support for mental illness patients-http://www.nami.org/; HelpLine 1 (800) 950-6264
- Healthy Minds- American Psychiatric Association resource center with articles on living with mental illness and treating those with mental illness. Information is targeted at particular population whether it be age, ethnicity, stage in life as well as organized by diagnosis- www.healthyminds.org
- National Mental Health Consumers' Self Help Clearinghouse- News & Alerts, training, publications, resources, and a Consumer-Driven Service Directory for those with mental illness looking to help themselves advocate and cope-http://mhselfhelp.squarespace.com/

- Depression & Bipolar Support Alliance- Education, training, treatment options, wellness tools, research, peer support, lifestyle tips, and outreach-http://www.dbsalliance.org/site/PageServer?pagename=home
- Anxiety & Depression Association of America- Information on different anxiety and mood disorders, resources guides, self-help materials, support, outreach, advocacy, personal testimonies, lifestyle tips, management and treatmenthttp://www.adaa.org/
- My Depression Connection, Anxiety Connection, Bipolar Connection-Information, FAQs, resources, support each with its own site.
 - Depression- http://www.healthcentral.com/depression/?ic=1102
 - Anxiety- http://www.healthcentral.com/anxiety/?ic=1102
 - Bipolar- http://www.healthcentral.com/bipolar/
- Wings of Madness- Information, latest research, lifestyle tips, treatment, diagnosis, and support for those diagnosed with Depression. This site was founded in 1995 and has been running since with the latest information on the mental illness- http://www.wingofmadness.com/
- 1800PPDMOMS- Part of the Kristin Brooks Hope Center, this is a website and hotline for mothers with Postpartum Depression or who suspect they might have PPD. Provides screening, support, and resources- http://www.1800ppdmoms.org/; 1 (800) 773-6667
- To Write Love On Her Arms- Organization dedicated to removing the stigma of depression, addiction, self-injury, eating disorders, suicide and bridging the gap between mental illness and treatment. Fundraising merchandise, blog entries, events. Founded by the founders of Hurley® - http://twloha.com/home
- o iFred- International Foundation for Research & Education on Depression is dedicated to removing the stigma or "rebranding" depression, providing timely resources for individuals with depression and their friends and families. Provides information on types of depression, management and treatment, support groups, online communities, national movement Field Of Hope- http://www.ifred.org/

Nursing

- o <u>www.care.com</u>
- o www.sittercity.com