

Blueprint for Caregiving

Start Now: Recommendations



*○ give thanks to the Lord, for he is good;
for his steadfast love endures forever...*

*For he satisfies the thirsty,
and the hungry he fills with good things.*

Psalm 107:1, 9

Websites Worth Visiting

To get you started now on building a meaningful and confident caregiving experience I have some websites to invite you to visit.

In “Search for Light,” I make it clear that it’s important educate yourself about your patient’s particular disease or condition and its treatment through websites. I’ve divided the following list into three categories—disease specific information, information for caregivers, and general information.

Before you get started on these specific sites, you can start your educational journey looking for caregiver support at the National Institutes of Health site (www.nih.gov), or at www.webmd.com. On either site, all you need to do is type “caregiving” into the search bar to find plenty of information and resources to help you in subjects ranging from burnout to financial concerns to navigating Medicare and Medicaid.

Recommended Websites

Disease Specific:

Alzheimer’s, Dementia and Brain Disorders

- Alzheimer’s Association, is informative about all kinds of dementia and provides link to local resources, www.alz.org.
- Alzheimer’s Weekly is an online magazine focused on various forms of dementia, but particularly Alzheimer’s disease, www.alzheimersweekly.com.
- For brain disorders, also known as neurological disorders, visit the National Institute of Neurological Disorders and Stroke (NINDS) at www.ninds.nih.gov.
- If your patient has been diagnosed with a brain tumor, there are five very helpful sites (though I wonder if we need this many competing non-profits in the brain tumor world): the American Brain Tumor Association, www.abta.org; the Brain Tumour Foundation of Canada, www.btfc.org; the National Brain Tumor Society, www.brainumor.org; the Children’s Brain Tumor Foundation, www.cbtf.org, and the National Brain Tumor Foundation, www.nbtf.org. The good news is that these groups, plus a few others interested in brain tumors, have pooled resources for a research project.
- For caregivers to patients with brain disorders, as well as other disabilities there is information at www.disabled-world.com.

Autoimmune Conditions

- Autoimmune conditions such as lupus and mixed connective tissue disorders (MCTD) has a foundation that has a website at www.lupusmctd.com.

Cancer

- The U. S. government also has a site for the Cancer Institute of the National Institutes of Health. That site is www.cancer.gov, and is in Spanish and English. It features a dictionary of cancer terms, a drug directory, lists of clinical trials, and standard treatments.
- The American Cancer Society, www.cancer.org, has a huge list of every type of cancer known, as well as an information service entitled, I Need Information For...Patients, Family and Friends.
- A website for working women with cancer, www.cancerandcareers.org, is sponsored by the Avon Foundation and provides information for patients and caregivers as well as links.
- Cancer patients who are taking chemotherapy treatments will want to visit www.chemotherapy.com. This site, supported by the drug company Amgen, has extensive information about the disease, treatment and even tax consequences. There's also a page for caregivers.
- Another good cancer website is www.curetoday.com. It is affiliated with Cure Magazine and is the lay arm of Medical Media Holdings, which is a company that provides continuing education for physicians.
- <http://lcl.patientadvocate.org> is a site for patients suffering from lymphedema.

Diabetes

- The American Diabetes Association site, www.diabetes.org is also in Spanish and English. It has a wealth of information including recipes, exercise programs and a question-and-answer section entitled For Parents and Kids.

Elder Care

- The Administration on Aging, www.aoa.gov. The federal government's Department of Health and Human Services oversees this site featuring information about federal programs to support caregivers. The information is offered in a half-dozen languages as well as English.
- Elder Care On-line, www.ec-online.net. Sponsored by a for-profit organization, QuietCare, this site has an abundance of information along with product offers.
- Health and Age Foundation's Caregivers Center, www.healthandage.com. This site from Boomerang Pharmaceutical Communications has a wide range of information on the subjects of health and age for lay people. Its Caregiver's Center features articles with tips and resources for caregivers.
- Senior Health site, www.nihseniorhealth.gov. This is part of the National Institutes of Health.

Heart Disease

- The American Heart Association, www.americanheart.org, is also bilingual and features a heart attack and stroke encyclopedia.

Lung Diseases

- The American (or Canadian) Lung Association at www.lungassociation.org is primarily a link to local lung associations.

Parkinson's and Movement Disorders

- For information on Parkinson's disease and links to local resources, go to www.allaboutparkinsons.com. This is a one-woman site, and she's selling her book and other material, but it also contains some useful practical information. See also www.ninds.nih.gov.

Spinal Cord Injury

- If you're looking for inspiration along with information, go to www.likemike.us. Mike and Betsy Thomas share their story of his SCI and his amazing effort to regain use of his legs.
- There are three sites to look at if your patient is suffering from a spinal cord injury—www.spinalinjury.net, www.makoa.org, and www.spinalcord.org. There are literally hundreds of SCI sites, but many too many of them are sponsored by personal injury lawyers. These three offer useful information without the ambulance-chasing ambiance.

Stroke

- There's lots of basic information at www.ninds.nih.gov which covers stroke as well as other neurological disorders.
- If you're a caregiver to a stroke or aphasia patient, you can find help at www.squidoo.com/strokecaregiver.

Traumatic Brain Injury

- There are two broad-based sites are from the U. S. government at www.ninds.nih.gov, and www.cdc.gov/ncipc/tbi.
- At www.biausa.org, you will find the helpful site of the American Brain Injury Association.
- I cautiously recommend a law-firm supported site in this case because it is so comprehensive, www.traumaticbraininjury.com.

For Caregivers:

- www.aarp.org/family/caregiving. There is a wealth of information and Gail Sheehy writes a regular feature about caregiving as AARP's Ambassador of Caregiving.
- www.blueprintforcaregiving.com is my website and includes a page where you can post messages and ask questions.
- Today's Caregiver Magazine has a website full of information for caregivers, www.caregiver.com.
- www.caregiver.on.ca from the Caregiver Network, Inc. of Canada, it is a broad-based informational site for Canadian caregivers.
- There are free blog sites which enable patients—or caregivers—to stay in touch with a large number of people, www.caringbridge.org and www.carepages.com. Carepages has links to help the caregivers and patients find support groups.

- There is an on-line community for caregivers, at www.caringroad.org. It's free and allows caregivers to contact one another. It's an online support group!
- Families of Loved Ones (FOLO) is another good, general caregiving site. Find it at www.cantwellmedia.com.
- www.fianationalnetwork.org, provides links to Faith in Action volunteers to assist caregivers in local communities in 48 states, Puerto Rico and the Virgin Islands.
- Johnson and Johnson, which makes medical products, sponsors a site that's good for caregiving information at www.strengthforcaring.com.
- www.lotsacaringhands.com is a free blog site to help caregivers coordinate help from family and friends.
- Medicare has caregiving information on its website at www.medicare.gov/caregivers.
- National Alliance for Caregiving, www.caregiving.org. This site focuses on caregiving issues, and offers information as well as resources.
- National Center on Caregiving, www.caregiver.org. This is the website of the Family Caregiving Alliance and has information on a broad range of caregiving topics, including legislation and research.
- National Family Caregivers Association, www.nfcacares.org. This organizations works in education, support, empowerment and advocacy for caregivers.
- National Family Caregiver Support Program, www.fullcirclecare.org. Titled the Full Circle of Care, this website provides extensive information and links to other caregiving sites and resources.

General Information:

- If you are looking for clinical trials in which your patient might be enrolled, go to www.clinicaltrials.gov. This site provides a comprehensive list of government and private trials that are seeking human volunteers.
- If you are looking for paid help in caring for an elderly loved one, the U. S. Administration on Aging has a database of caregivers at www.eldercare.gov.
- At www.familydoctor.org, the site of the American Academy of Family Physicians, you will find a long list of diseases and conditions, as well as health tips and a directory of physicians.
- The U. S. Department of Health and Human Services has a great site at www.healthfinder.gov. In Spanish and English, it has a list of diseases, and disease-related organizations, a prescription drug database and more than 50 different on-line check ups.
- Livestrong is a site from the Lance Armstrong Foundation that covers a wide range of diseases and conditions and offers suggestions to caregivers. You find it at www.livestrong.com.

- The Mayo Clinic site, www.mayoclinic.com also lists diseases and conditions, has a complementary and alternative medicine page and a list of drugs and supplements. Most importantly it has a page entitled Treatment Decisions to assist patients in making their own treatment decisions.
- MedlinePlus, www.medlineplus.gov is the site of the National Library of Medicine. It features a dictionary, directories, a medical encyclopedia, as well as a list of health topics and drugs and supplements.
- National Institutes of Health is an umbrella site that contains several disease and condition-specific sites, www.nih.gov.
- If you are looking for a patient advocate to help you and your loved one with the medical system, try www.patientadvocate.org. For those who need bone marrow or blood-cell transplants, advocates can be found at www.marrows.org.
- www.pdrhealth.com is another good general resource. It's the website of the publishers of the Physicians' Desk Reference, an encyclopedia of professional information for doctors. This site is for lay people.
- At US News and World Report's web site, www.usnews.com, there is a comprehensive list of diseases and conditions with plenty of good, basic information about the diagnosis, treatments and standard outcomes. From the home page, click on the Health tab then click on the tab reading diseases and conditions. There is also a web-based community for sharing information and experiences.
- WebMD is another terrific, very helpful general site, www.webmd.com.
- The Department of Defense has a good website for wounded military people, www.woundedwarriorresourcecenter.com.
- Finally, many university medical schools and hospitals can be sources for caregiving information. The address would be [www.\(name of the university\).edu](http://www.(name of the university).edu). Look for tabs to pages in the medical school or university hospital on a specific disease/condition or caregiving.