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Websites and Resources for Cancer Family Caregivers

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In the United States, over the past 12 months, more than 48 million people report serving as a family caregiver (FCG) for an adult loved one (National Alliance for Caregiving, 2009; Northouse, Katapodi, Schafenacker, & Weiss, 2012). The caregivers identify cancer as one of the most common illnesses of their care recipients. Remarkably, cancer FCGs provide an estimated 75% to 80% of their loved ones' care over the disease trajectory. With predictions of 1.7 million new cancer diagnoses (Siegel, Naishadham, & Jemal, 2012; 2013) and more than 13 million cancer survivors (de Moor et al., 2013; O'Brien, Ness, Anderson, Sborov, & Foster, 2013), reliance on cancer FCGs will continue to increase.

Cancer health-care professionals have years of preparatory training for the physical, psychological, social, and spiritual complexities of cancer care. In contrast, FCGs, who provide the bulk of the care, are generally suddenly thrust into the caregiver role with minimal training and limited institutional support (van Ryn et al., 2011). Many FCGs feel anxious, ill prepared, and unsupported in their new roles (Ford, Catt, Chalmers, & Fallowfield, 2012) and look to the multidisciplinary oncology team—especially advanced practitioners (APs)—for information and support. To bridge the gap from being an ill-prepared, minimally supported caregiver to being a confident, knowledge-based caregiver, awareness and access to quality, reliable resources are essential. Increasingly, FCGs are going to the Internet to search for information. In fact, 8 out of 10 caregivers (79%) have access to the Internet. Of those, 88% look online for health information (Fox & Brenner, 2012).

The 2008 Institute of Medicine (IOM) report, *Retooling for an Aging America: Building the Health Care Workforce,* recommends patients and caregivers be considered essential parts of the health-care team and active participants in the health-care plan. Moreover, the report suggests, for caregivers to be effective members of the team, they need to have the necessary data, knowledge, and tools to provide high-quality care (IOM, 2008). To promote caregivers' effective collaboration on the health-care team, resources need to include up-to-date, easily accessible information such as that featured on a page of the National Cancer Institute (NCI) website, entitled Family Caregivers in Cancer: Roles and Challenges (NCI, 2013).

CARING FOR THE PATIENT

To help FCGs get the support they need, APs must understand the complexity of problems and responsibilities associated with the cancer caregiver experience. Furthermore, APs must be prepared to assist FCGs in finding accurate, up-to-date information, especially online resources (see Tables 1 and 2).

Throughout the illness trajectory, caregivers deal with a multitude of new experiences: navigating a complex health-care system, procuring/dispensing medications, monitoring/managing symptoms, providing wound care, communicat-

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Table 1. Selected Cancer Caregiver Websites

Resource/website	Description
American Cancer Society www.cancer.org/treatment/caregivers/index	Information and literature for FCGs to learn about what to expect if they become a caregiver for a person with cancer; suggestions and tips for taking care of oneself as well
Cancer Hope Network www.cancerhopenetwork.org	Free and confidential one-on-one support for cancer patients and their caregivers; trained volunteers who have undergone and recovered from a similar cancer experience are matched with patients or caregivers in need of support
Cancer Legal Resource Center www.disabilityrightslegalcenter.org/about/cancerlegalresource.cfm	Free information on cancer-related legal issues for caregivers, survivors, health-care professionals, employers, and others
Cancer Support Community www.cancersupportcommunity.org/MainMenu/Family-Friends/Caregiving	Emotional and social support, a network of community-based centers and online services run by trained and licensed professionals; education and support (*Frankly Speaking* series)
CancerCare www.cancercare.org/tagged/caregiving	Free support, information, financial assistance, and practical help for people with cancer and their caregivers; services available in person, over the phone, and through the agency's website
Joe's House www.joeshouse.org	Nationwide housing guide for cancer patients and their families traveling for treatment; directories of various places to stay near cancer treatment centers
Leukemia & Lymphoma Society www.lls.org/#/diseaseinformation/forcaregivers/	Information and support for caregivers of people with cancer; offers education, support groups/programs; resources
My Cancer Circle mycancercircle.lotsahelpinghands.com/caregiving/home/	Free, private support community for caregivers of people facing cancer, online tool to help organize the community of people who want to help, and resources provided directly from Cancer*Care* that can help FCGs in their role as caregivers
National Cancer Institute cancer.gov/cancertopics/coping/familyfriends NCI Sub-link: Family Caregivers in Cancer www.cancer.gov/cancertopics/pdq/supportivecare/caregivers/patient	Information to help caregivers cope while caring for a loved one with cancer; cancer information summaries, reviewed regularly and updated as new information becomes available
National Comprehensive Cancer Network www.nccn.com/cancer-caregiver.html	Provides resources, article, and videos with advice on how to help a loved one with cancer and how to take care of oneself
Young Cancer Spouses www.youngcancerspouses.com	Brings together young spouses of adults with cancer to share information, support, and experiences; provides information on taking care of self, medical care, relationships, financial issues, transitions; and has an online forum to connect with others

Note. FCG = family caregiver.

ing with providers, providing emotional support, dealing with insurance, transporting to/from appointments, and managing side effects from treatment. The dynamic nature of cancer requires that the FCG always be "on call" to solve problems and make decisions as care needs change (Schubart, Kinzie, & Farace, 2008). Providing resources that consider these evolving needs promotes self-confidence in caregivers who are more prepared to anticipate and adjust to their shifting responsibilities. For example, the resources found on the American Cancer Society (ACS) website have extensive information on what to expect as a caregiver of a cancer patient (ACS, 2013).

CARING FOR SELF

Along with providing care for their loved one, FCGs have needs of their own: sleep, nutrition, exercise, social support, medical appointments/adherence to their own medical regimens, spiritual health, and respite from care responsibilities (Son et al., 2012). Too often these needs are

Table 2. General Caregiver Websites

Resource/website	Description
Aging Parents and Elder Care www.aging-parents-and-elder-care.com/	Caring for aging parents and other elderly seniors: daily living solutions, support groups, free referral service to help find everything from home care and assisted living to financial planning and personal emergency responses
American Association of Retired Persons www.aarp.org/relationships/caregiving-resource-center/	Caregiving Resource Center: support line, resources, tools, work sheets, and tips on how to plan, prepare, and succeed as a caregiver
Caregiver Action Network www.caregiveraction.org	Pathways for caregivers tailored for specific situations, e.g., long-distance caregiving, online support groups, peer network, family caregiver toolbox, links to agencies/organizations, and a project to share stories
Caregiving 101 www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=2448	Archived webinar provides caregivers with the basic tools, skills, and information needed to protect their own physical and mental health while they provide high-quality care for their loved one
Caregiving.com www.caring.com/home-care	Help in finding and paying for FCGs providing in–home care; disease-specific information; ask-the-expert question/answer caregiver blog
CarePages www.carepages.com	Patient blogs that connect friends and family during a health challenge; discussion forums connect caregivers with other caregivers
Caring from a Distance www.cfad.org	Website for distance caregivers, links to resources across the US; especially helpful for crisis and emergency assistance
CaringBridge www.caringbridge.org	Free personal and private websites connecting people experiencing a health challenge with family and friends; Support Planner calendar helps coordinate care and organize daily tasks
CMS—Centers for Medicare and Medicaid Services (formerly HCFA) www.cms.hhs.gov	Government-agency website information about Medicare and Medicaid programs, access to consumer publications and forms, e-mail access to customer service, and local contacts; two publications that deal specifically with caregiving: *Medicare Basics: A Guide for Caregivers* and *When Employees Become Caregivers: A Manager's Workbook*
Family Caregiver Alliance (FCA) http://www.caregiver.org/caregiver/jsp/home.jsp	Information on public policy and research for caregivers; a navigator to help find resources/services in your area; discussion groups
Full Circle of Care www.fullcirclecare.org/caregiverissues/welcome.html	Information and links to personalized assistance for FCGs of older adults. Help to understand the issues, know how to access help, and what questions to ask and what to look for when you do get connected locally
Healthcare Hospital Network www.nahhh.org	List of facilities that provide lodging and other supportive services to families and patients receiving medical treatment away from home
Lotsa Helping Hands www.lotsahelpinghands.com	Brings together caregivers and volunteers through online communities that organize daily life; provides a free easy-to-use, private individualized group calendar, specifically designed for organizing helpers
National Alliance for Caregiving www.caregiving.org/resources	A nonprofit coalition of national organizations focusing on issues of family caregiving, education, resources, and advocacy
National Caregiving Foundation www.caregivingfoundation.org	Caregiver's Support Kit provides educational information for caregivers
National Institute on Aging www.nia.nih.gov/search/site/caregiver	Wide variety of research-based information and resources related to health and aging, including multiple caregiver resource links
NIH MedlinePlus: Caregivers www.nlm.nih.gov/medlineplus/caregivers.html	Produced by the National Library of Medicine, this site provides free information about diseases, conditions, and wellness issues in clear language for laypeople
Strength for Caring: A Place for Caregivers www.strengthforcaring.com	Caring for oneself while caring for others; tips on daily care and information about health conditions; tips on housing, finance, insurance, and other concerns
UCSF Osher Center for Integrative Medicine www.osher.ucsf.edu/patient-care/self-care-resources/caregivers/	Information and resources for FCGs on navigating the health-care system, communicating with physicians, understanding insurance coverage, and caring for oneself
US Department of Veterans Affairs Caregiver Support Services www.caregiver.va.gov/support_landing.asp	Services designed to support the FCG caring for a veteran; support and service options designed with the caregiver in mind; the programs are available both in and out of the home to help care for the veteran and the FCG
Well Spouse Association www.wellspouse.org	Resources and advocacy for individuals caring for a chronically ill and/or disabled spouse/partner; peer-to-peer support

Note. FCG = family caregiver.

pushed aside while caregivers focus on caring for the cancer patient. Studies have shown that FCGs frequently experience a decline in their own health and quality of life as a consequence of their caregiver role (Stenberg, Ruland, & Miaskowski, 2010). Encouragement from APs and access to reliable, high-quality caregiver-focused resources help FCGs take care of their own health needs and improve their quality of life. For instance, support groups such as those found through the CancerCare (CancerCare, 2013) and Cancer Support Community (Cancer Support Community, 2013) websites can be important resources to help strengthen the FCG's psychological well-being.

CONCLUSIONS

As the cancer care setting continues to shift from the hospital to the home, demands on FCGs accelerate. Increasingly, caregivers rely on healthcare providers—especially APs—for guidance as they struggle to provide quality care for their loved one. Caregivers are eager for online resources that are accurate, pertinent, clear-cut, and easily accessible. Tables 1 and 2 give APs a list of resource websites to offer to FCGs as they care for their loved one throughout the cancer journey. Table 1 provides selected websites specifically developed for cancer FCGs. In addition, Table 2 offers valuable websites that will be helpful for all FCGs caring for a loved one experiencing health issues.

DISCLOSURE

The authors have no conflicts of interest to disclose.

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