



## **Hospital Warrior: How to Get the Best Care for Your Loved One by Bonnie Friedman**

### **Finding More Information**

Hospital Warrior includes many references for additional information on a range of topics. This resource provides updated, online access to sites to help you get the details you need.

Contact information is as accurate as possible, but phone numbers and website addresses are subject to change. Please let me know if you find updated information in your search for information.

### **Advocacy**

#### **Patient Advocate Foundation**

[www.patientadvocate.org](http://www.patientadvocate.org)

800-532-5274

Provides legal support and services to help patients solve insurance and healthcare access problems; also offers education, resources and advocacy.

#### **Patient Rising**

[www.patientsrising.org](http://www.patientsrising.org)

800-685-2654

Provides education, resources to help patients and their caregivers advocate for the care and treatment they need to live a fulfilling life.

#### **Well Spouse Association**

[www.wellspouse.org](http://www.wellspouse.org)

800-838-0879

Provides support and education about the challenges facing spousal caregivers including resources, support groups, events and more.

### **Affordable Care Act**

#### **Healthcare.gov**

[www.healthcare.gov/health-care-law-protections/](http://www.healthcare.gov/health-care-law-protections/)

800-318-2596

U.S. federal government website managed by the U.S. Centers for Medicare & Medicaid Services providing information about the act, how to sign up, legal protections and more.

- See also: [www.cms.gov/ccio/resources/Regulations-and-Guidance/index.html](http://www.cms.gov/ccio/resources/Regulations-and-Guidance/index.html)

### **Department of Veterans Affairs**

[www.va.gov/health/aca/](http://www.va.gov/health/aca/)

800-827-1000

Specific information about the Affordable Care Act for veterans and their families.

### **Aging**

#### **Aging with Dignity**

[www.AgingWithDignity.org](http://www.AgingWithDignity.org)

888-594-7437

National non-profit organization devoted to affirming the human dignity of individuals as they age and to promote better care for those near the end of life.

#### **American Association of Retired Persons (AARP)**

[www.aarp.org](http://www.aarp.org)

888-687-2277

Nonprofit organization that helps individuals, strengthens communities and advocates for issues including healthcare. Click on Health for information about medical issues, healthcare news, Medicare, health insurance, prescription drugs and more.

### **Caregiving**

#### **AARP Caregiving Resource**

[www.aarp.org/caregiving](http://www.aarp.org/caregiving)

877-333-5885

Nonprofit organization providing a wealth of information including tools and tips for caregivers such as expert advice, support groups, local resources, caregiving issues and news.

#### **Aging Life Care Association**

[www.aginglifecare.org](http://www.aginglifecare.org)

520-881-8008

Professional association representing senior care providers; website offers a tool to search for certified professionals by zip code.

**Caring Bridge**

[www.caringbridge.org](http://www.caringbridge.org)

651-452-7940

Nonprofit organization that allows family and friends to create personal, private websites to stay connected, provide updates and support one another during a loved one's illness.

**Caring Connections**

[www.caringinfo.org](http://www.caringinfo.org)

800-658-8898

A program of the National Hospice and Palliative Care Organization, provides information and support for making life plans, caring for a loved one who is living with an illness or grieving a loss.

**Eldercare Locator**

[www.eldercare.acl.gov](http://www.eldercare.acl.gov)

800-677-1116

A public service of the U.S. Administration on Aging connecting individuals to services for older adults and their families.

**Family Caregiver Alliance**

[www.caregiver.org](http://www.caregiver.org)

800-445-8106

Community-based, nonprofit organization that addresses the needs of families and friends providing long-term care for loved ones. Focuses on caregiver services, policy and research; offers support and education on multiple topics of interest.

**Inspire**

[www.inspire.com](http://www.inspire.com)

800-945-0381

Provides patients and caregivers with support networks for learning and sharing information related to medical conditions, treatment and support.

**National Caregivers Library**

[www.caregiverslibrary.org](http://www.caregiverslibrary.org)

804-327-1111

Free tools for caregivers including checklists, forms, and other resources to help make decisions and get organized.

**Next Step in Care**

[www.nextstepincare.org/caregiver\\_home](http://www.nextstepincare.org/caregiver_home)

212-494-0700

United Hospital Fund program offers guides to help family caregivers and healthcare professionals work together on transitions from hospital, to nursing or rehabilitation facility, and/or to home.

### **Lotsa Helping Hands**

[www.lotsahelpinghands.com](http://www.lotsahelpinghands.com)

Brings together caregivers and volunteers through online communities that help organize daily life during times of medical crisis or caregiver exhaustion and coordinate services that are needed.

### **Mealtrain**

[www.mealtrain.com](http://www.mealtrain.com)

Simplifies the organization of meal giving around significant life events; promotes interpersonal relationships among friends, families, and neighbors through meals.

### **U.S. Department of Veterans Affairs**

[www.caregiver.va.gov](http://www.caregiver.va.gov)

855-260-3274

Offers services and support for caregivers of veterans. Programs are offered in and out of the home. Additional information at:

[www.caregiver.va.gov/support/support\\_services.asp#sthash.xV2r2QGB.dpuf](http://www.caregiver.va.gov/support/support_services.asp#sthash.xV2r2QGB.dpuf)

### **Clinical Trials**

#### **Clinicaltrials.gov**

[www.clinicaltrials.gov/ct2/about-studies/learn](http://www.clinicaltrials.gov/ct2/about-studies/learn)

888-346-3656

Maintained by the National Library of Medicine, part of the National Institutes of Health, a data base of privately and publicly funded clinical studies conducted around the world. See special pages for patients and families.

### **Food and Drug Administration**

[www.fda.gov](http://www.fda.gov)

888-463-6332

U.S. federal agency responsible for assuring the safety, efficacy and security of drugs, biological products, medical devices, food supply, cosmetics and more. Provides for expanded access to some experimental treatments for certain patients with life-threatening illnesses.

## **Electronic Medical and Legal Tools**

### **HealthIT**

[www.healthit.gov](http://www.healthit.gov)

202-690-7151

The Office of the National Coordinator for Health Information Technology; click on “For Individuals” for information on accessing and protecting online health information.

### **My Health Care Wishes**

[www.americanbarfoundation.org](http://www.americanbarfoundation.org)

312-988-6500

American Bar Foundation’s smart phone app providing storage and management of personal and family documents including advance directives, living wills, Do Not Resuscitate orders and more. Enter “My Health Care Wishes” into your search engine for best results.

## **End-of-Life Planning**

### **American Association of Retired Persons**

[www.aarp.org/relationships/caregiving-resource-center/info-11-2010/lfm\\_living\\_will\\_and\\_health\\_care\\_power\\_of\\_attorney.html](http://www.aarp.org/relationships/caregiving-resource-center/info-11-2010/lfm_living_will_and_health_care_power_of_attorney.html)

888-687-2277

Nonprofit organization that helps individuals, strengthens communities and advocates for issues including healthcare. Also provides information and resources on end-of-life planning.

### **American Bar Association**

[www.americanbar.org/groups/law\\_aging/resources/health\\_care\\_decision\\_making/consumers\\_toolkit\\_for\\_health\\_care\\_advance\\_planning](http://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumers_toolkit_for_health_care_advance_planning)

800-285-2221

Professional association serving the legal profession; offers numerous resources including Consumer’s Toolkit for Health Care Advance Planning.

### **CaringInfo**

[www.caringinfo.org](http://www.caringinfo.org)

800-658-8898

A program of the National Hospice and Palliative Care Organization; provides advance directives to individuals free of charge, along with additional resources and information to help people make decisions about end-of-life care and services.

**Centers for Medicare and Medicaid Services**

[www.medicare.gov/manage-your-health/advance-directives/advance-directives-and-long-term-care.html](http://www.medicare.gov/manage-your-health/advance-directives/advance-directives-and-long-term-care.html)

800-633-4227

Official federal site for U.S. Medicare and Medicaid; offers wealth of resources including information on advance directives and long-term care.

**Compassion and Choices**

[www.compassionandchoices.org](http://www.compassionandchoices.org)

800-247-7421

Nonprofit organization committed to helping everyone have the best death possible; offers free counseling, planning resources, referrals and guidance; works to protect and expand options at the end of life.

**The Conversation Project**

[theconversationproject.org](http://theconversationproject.org)

617-391-9913

Dedicated to helping people talk about their wishes for end-of-life care. Offers a conversation starter kit, shared stories, blog and other resources to help people have the conversation.

**Death with Dignity**

[www.deathwithdignity.org/advocates/national](http://www.deathwithdignity.org/advocates/national)

503-228-4415

Promotes Death with Dignity laws and provides information, education and support to patients, family members, legislators, advocates, health professionals, the media and the public.

**Weill Cornell Medical College**

<https://medicine.weill.cornell.edu/divisions-programs/medical-ethics/clinical-ethics>

212-746-5454

Offers ethics consultation service for clinicians, patients and families to help assess and resolve clinical ethical issues.

**Emergency Medical Treatment and Labor Act****Centers for Medicare and Medicaid Services**

[www.cms.gov/Regulations-and-Guidance/Legislation/EMTALA/index.html?redirect=/EMTALA/](http://www.cms.gov/Regulations-and-Guidance/Legislation/EMTALA/index.html?redirect=/EMTALA/)

800-633-4227

U.S. federal law ensuring public access to emergency medical services regardless of ability to pay.

### **Health Insurance Portability and Accountability Act**

#### **U.S. Department of Health and Human Services**

[www.hhs.gov/ocr/hipaa](http://www.hhs.gov/ocr/hipaa)

202-690-7000

U.S. federal government site providing official information about the health care privacy law and its application.

- Sharing Health Information with Family Members and Friends fact sheet

<https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/consumers/sharing-family-friends.pdf>

### **Healthcare Provider Ratings**

#### **Care.com**

[www.care.com](http://www.care.com)

781-642-5900

Provides resources for choosing homecare, companionship and other support services; includes tools to help interview and hire individuals for employment. Must join for free.

#### **Healthcare.gov**

[www.healthcare.gov/where-can-i-find-provider-information](http://www.healthcare.gov/where-can-i-find-provider-information)

800-318-2596

U.S. federal website that offers multiple tools to search, compare, and assess providers, hospitals, and other care facilities including doctors, other healthcare providers, nursing homes and more.

#### **Healthgrades.com**

[www.healthgrades.com](http://www.healthgrades.com)

844-247-2717

Provides consumers with the information to make informed healthcare decisions, including information about provider experience, patient satisfaction and hospital quality.

#### **Medicare**

[www.medicare.gov](http://www.medicare.gov)

800-633-4227

U.S. Federal agency website providing vast information on the Medicare program as well as finding care providers and comparing costs; click on providers and services.

## **US News and World Report**

[https://health.usnews.com/?int=top\\_nav\\_Health](https://health.usnews.com/?int=top_nav_Health)

212-716-6800 X3

Popular news magazine with national assessments in multiple categories including health care. Check ratings for hospitals, doctors, senior care, over-the-counter treatments and more.

## **Home Healthcare**

### **Administration for Community Living**

<https://acl.gov>

202-401-4634

- Eldercare Locator (to find local resources):  
800-677-1116

U.S. federal agency providing interactive locator to find programs and services in areas including long-term care, aging, disability and advocacy.

## **Hospice and Palliative Care**

### **Centers for Medicare and Medicaid Services**

[www.medicare.gov/Pubs/pdf/02154.pdf](http://www.medicare.gov/Pubs/pdf/02154.pdf)

800-633-4227

U.S. federal agency which administers Medicare, Medicaid, and the State Children's Health Insurance Program. Provides array of information for health professionals, patients, families and the general public, including the Medicare Hospice Benefits booklet. Enter Hospice and Palliative Care in the search bar for best results.

### **Caring Community**

[www.caringcommunity.org](http://www.caringcommunity.org)

707-539-2364

An online resource for planning for or living with serious illness and end-of-life issues. Includes multiple resources, publications, advocacy and support groups.

### **Compassion and Choices**

[www.compassionandchoices.org](http://www.compassionandchoices.org)

800-247-7421

Nonprofit organization committed to helping everyone have the best death possible; offers free counseling, planning resources, referrals and guidance including a state locator for services; works to protect and expand options at the end of life.



### **International Association for Hospice and Palliative Care**

<https://hospicecare.com/home/>

866-374-2472

National organization dedicated to increasing availability of quality palliative care services for people and families facing serious, complex illness. Website offers numerous resources including a directory of institutions and organizations.

### **National Hospice and Palliative Care Organization**

[www.caringinfo.org](http://www.caringinfo.org)

800-658-8898

Provides information, resources and support for patients and families for planning ahead, caregiving, living with serious illness or grieving loss.

- NHPCO locator for finding hospice, palliative care, and bereavement service providers near you:

<https://www.nhpco.org/find-a-care-provider/>

### **National Institutes of Health**

[www.nlm.nih.gov/medlineplus/palliativecare.html](http://www.nlm.nih.gov/medlineplus/palliativecare.html)

301-496-4000

U.S. federal medical research agency, National Library of Medicine; offers consumer medical and health information on wide range of topics; provides community and science education resources, publications and phone numbers for a wide range of issues including palliative care.

## **Hospital Ratings**

### **Hospital Consumer Assessment of Healthcare Providers and Systems**

[www.medicare.gov/hospitalcompare/search.html#](http://www.medicare.gov/hospitalcompare/search.html#)

800-633-4227

Administered by U.S. Medicare program, HCAHPS scores provide information about quality of care at over 4,000 hospitals across the country based on patients' experiences

### **The Leapfrog Group**

[www.hospitalsafetyscore.org](http://www.hospitalsafetyscore.org)

202-292-6713

Hospital assessments based on voluntary survey participation; evaluations cover three key areas: how patients fare, resources used in caring for patients, and leadership and structures that promote patient safety.

**U.S. News & World Report**

[health.usnews.com/best-hospitals](http://health.usnews.com/best-hospitals)

212-716-6800

Rankings for the best adult and children's hospitals based on analysis of data from nearly 5,000 centers; includes special analysis of how hospitals performed in heart bypass surgery, hip replacement, knee replacement, heart failure and chronic obstructive pulmonary disease.

**Magnet Hospitals****American Nurses Credentialing Center**

[www.nursingworld.org](http://www.nursingworld.org)

800-284-2378

Aligned with the American Nurses Association, recognizes healthcare organizations for quality patient care, nursing excellence and innovations in professional nursing practice. Click on Magnet to locate participating hospitals.

**Medical Information****eMedicineHealth**

[www.emedicinehealth.com](http://www.emedicinehealth.com)

Consumer health information site containing more than 900 health and medical articles with a focus on emergency medicine, written by physicians for patients and consumers.

**Jerome Groopman, MD**

[www.jeromegroopman.com](http://www.jeromegroopman.com)

Acclaimed physician, Harvard Medical School professor and author, his website provides information about books, articles, links to media coverage and interviews, as well as contact information. Click on Articles for links to a wealth of insight and information.

**Mayo Clinic**

[www.mayoclinic.org/patient-care-and-health-information](http://www.mayoclinic.org/patient-care-and-health-information)

507-284-2511

Recognized leader in medical care, research and education; provides patient care and health information on wide range of topics from physicians, scientists and other medical experts.

**MedicineNet**

[www.medicinenet.com](http://www.medicinenet.com)

212-624-3700

Part of the WebMD network, this online healthcare media publishing company providing easy-to-read, in-depth, authoritative medical information for consumers via a user-friendly, interactive website; content produced by a network of more than 70 U.S. board-certified physicians.

**MedlinePlus**

[www.nlm.nih.gov/medlineplus](http://www.nlm.nih.gov/medlineplus)

888-346-3656

A service of the U.S. National Library of Medicine, which is part of NIH and the world's largest medical library, provides top-quality health and wellness information in English and Spanish.

**National Institutes of Health**

[www.nih.gov](http://www.nih.gov)

301-496-4000

U.S. federal agency that conducts and supports wide-ranging medical research; provides healthcare information on many topics and offers tools and resources in multiple languages to aid in decision-making.

**National Institute on Aging**

[www.nia.nih.gov](http://www.nia.nih.gov)

800-222-2225

One of the institutes of the U.S. NIH, conducts and supports research on aging; also provides a wealth of information on Alzheimer's, caregiving, doctor-patient communication and much more. Click on Institutes at NIH, then NIA.

**Prepare**

[www.prepareforyourcare.org](http://www.prepareforyourcare.org)

info@prepareforyourcare.org

An online program to help patients and families talk with doctors, make medical decisions and get the medical care they need.

**WebMD**

[www.webmd.com](http://www.webmd.com)

212-624-3700

Provides informative, reliable health information, tools for managing health, and support for those seeking health information as well as additional material from well-known content providers.

## **Medicaid**

### **Medicaid.gov**

[www.medicaid.gov](http://www.medicaid.gov)

877-267-2323

Part of the federal Centers for Medicare and Medicaid Services, the site provides policy and program information about Medicaid, the Children's Health Insurance Program and the Basic Health Program.

## **Medicare**

### **Medicare.gov**

[www.medicare.gov](http://www.medicare.gov)

877-267-2323

The U.S. federal government's official site for all things Medicare including coverage, plan options, benefits, policies, publications and more. Don't overlook the Resources link/Find Local Help for added connections.

### **Center for Medicare Advocacy**

[www.medicareadvocacy.org](http://www.medicareadvocacy.org)

202-293-5760

Nonprofit legal organization that works to expand access to Medicare coverage, health equity and quality care for older people and those with disabilities.

### **State Health Insurance Assistance Programs (SHIPs)**

[www.shiphelp.org](http://www.shiphelp.org)

877-839-2675

National program that offers local, authoritative insurance counseling to Medicare-eligible individuals, their families and caregivers; answers questions about benefits, coverage and rights under the Medicare program.

## **Patients' Rights**

### **Affordable Care Act**

<https://www.hhs.gov/healthcare/index.html>

800-318-2596

Information about health insurance coverage, the insurance marketplace and additional resources.

**American Hospital Association**

[www.aha.org/advocacy-issues/communicatingpts/pt-care-partnership.shtml](http://www.aha.org/advocacy-issues/communicatingpts/pt-care-partnership.shtml)

312-422-3000

The AHA Patient Care Partnership brochure informs patients about what they should expect during their hospital stay with regard to their rights and responsibilities.

**President's Advisory Commission Consumer Bill of Rights and Responsibilities**

[archive.ahrq.gov/hcqual/press/cbor.html#head1](http://archive.ahrq.gov/hcqual/press/cbor.html#head1)

800-732-8200

Archived proposal of 1998 Consumer Bill of Rights and Responsibilities that was adopted by the U.S. Advisory Commission on Consumer Protection and Quality in the Health Care Industry.

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