

# PALLIATIVE CARE RESOURCES



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## ALZHEIMER'S DISEASE & DEMENTIA

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### Alzheimer's Association

Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

### Dementia Society of America

Our programs bring much-needed education, local resources, and life-enrichment to individuals and families, impacted by Dementia. We recognize caregivers and innovators, and raise HOPE by supporting relevant research to discover cures, causes, and meaningful interventions.

### Lewy Body Dementia Association

Through outreach, education and research, we support those affected by Lewy body dementias, their families and caregivers. We are dedicated to raising awareness and promoting scientific advances.

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## BREAST CANCER

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### Breast Cancer

CDC works with partners to reduce the burden of breast cancer in the U.S.A.

### Living beyond Breast Cancer

To connect people with trusted breast cancer information and a community of support.

### Share

SHARE is a national nonprofit that supports, educates, and empowers women affected by breast or ovarian cancer, with a special focus on medically underserved communities. SHARE meets women wherever they are with the insight of others who have been there too, creating a nationwide community where no one feels alone.

### Young Survival Coalition

Young women can and do get breast cancer. We believe that knowledge and understanding can make us all stronger. We hope these pages help you learn about breast cancer at your own pace—so you can feel more confident and in control of your health.

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## CANCER EDUCATION & ADVOCACY

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### American Cancer Society

ACS has more than 3,400 local community chapters who provide support, financial assistance and counseling for anyone affected by cancer.

### National Cancer Institute

#### Cancer 101

Cancer resources that empower patients, survivors, caregivers through individualized tool and resources.

#### Chemocare

Online resources about chemotherapy treatments and managing side effects, survivor forums, message boards, nutritional counseling and long-term concerns.

#### CURE

Care Media Group's flagship product, CURE magazine, is the guide to every stage of the cancer experience. Online resources are provided.

### National Cancer Institute

The National Cancer Institute coordinates the United States National Cancer Program and is part of the National Institutes of Health, which is one of eleven agencies that are part of the U.S. Department of Health and Human Services. Provides accurate, up-to-date, comprehensive cancer information from the U.S. government's principal agency for cancer research.

### National Comprehensive Cancer Network

NCCN is a not-for-profit alliance of 28 leading cancer centers devoted to patient care, research, and education. NCCN is dedicated to improving and facilitating quality, effective, efficient, and accessible cancer care so patients can live better lives.

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## CAREGIVER SUPPORT

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### AARP Home Alone Alliance

The "How-To" videos and resource guides for family caregivers are on specific medical/nursing tasks – including preparing special diets, managing incontinence, wound care, mobility, and managing medications.

### Family Caregiver Alliance

For 40 years Family Caregiver Alliance (FCA) has supported and sustained the important work of families and friends nationwide who care for adult loved ones with chronic, disabling health conditions.

### Care Pathways

Helping families find quality home care for their loved ones. Up-to-date research and data resources can still be found across CarePathways.com as we believe knowledge is key when caring for our aging loved ones.

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## CAREGIVER SUPPORT

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### Share the Care

To improve the quality of life for anyone who needs support and to reduce the stress, depression, isolation and economic hardship of their caregivers.

Long-Distance Caregiving (National Institute on Aging)

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## COLON CANCER

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### Colon Cancer Alliance

The Colorectal Cancer Alliance provides support to colon cancer patients and their families, while saving lives through screening, access, awareness, advocacy and research.

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## DONOR BLOOD DRIVES

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### DKMS Americas

Organizes donor drives to give every patient suffering from leukemia an equal chance to find a match. Connects marrow donors with patients in need.

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## FERTILITY PRESERVATION

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### Reprotech

Works with fertility services across the USA offering cryopreservation services.

### Oncofertility Consortium

MyOncofertility.org is a patient education resource from the Oncofertility Consortium, a national, interdisciplinary initiative exploring the reproductive future of cancer survivors.

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## GENERAL

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### Get Palliative Care

Get Palliative Care is a website providing clear, comprehensive palliative care information for people living with a serious illness. The site is provided by the Center to Advance Palliative Care (CAPC).

### Informed Patient Institute

Providing rated websites to help you find a doctor, hospital, and nursing homes in your state and tips about quality concern.

### National Resource on LGBT Aging

The National Resource Center on LGBT Aging is the country's first and only technical assistance resource center aimed at improving the quality of services and supports offered to lesbian, gay, bisexual and/or transgender older adults.

# PALLIATIVE CARE RESOURCES

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## GENERAL

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### [The Eldercare Locator](#)

Eldercare Locator, a public service of the U.S. Administration on Aging connecting you to services for older adults and their families.

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## GERIATRICS

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### [GeriPal](#)

GeriPal is a forum for discourse, recent news and research, and freethinking commentary. Our objectives are: 1) to create an online community of interdisciplinary providers interested in geriatrics or palliative care; 2) to provide an open forum for the exchange of ideas and disruptive commentary that changes clinical practice and health care policy; and 3) to change the world.

### [John Hartford Foundation](#)

The John Hartford Foundation is dedicated to improving the care of older adults and supports the spread of evidence-based models of care that can dramatically accelerate care improvements for older adults.

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## HEART DISEASE

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### [American Heart Association](#)

[Heart Disease](#) (Centers for Disease Control)

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## HIV

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### [AIDS United](#)

[AIDS.gov](#) an overview, prevention and testing information.

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## HOSPICE

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### [CaringInfo](#)

CaringInfo, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decision about services before a crisis.

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## INSURANCE AND COVERAGE OPTIONS

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[U.S. Department of Health and Human Services](#)

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## KIDNEY DISEASE

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[American Association of Kidney Patients](#)

[National Kidney Foundation](#)

# PALLIATIVE CARE RESOURCES

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## LEGAL & FINANCIAL

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### Medicare Rights Center

The Medicare Rights Center is a national, nonprofit consumer service organization that works to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs and public policy initiatives.

### Triage Cancer

Triage Cancer is a national, nonprofit organization that provides education on the practical, legal and financial issues that may impact individuals diagnosed with cancer and their caregivers.

### National Cancer Legal Services Network

The NCLSN promotes access to healthcare and seeks to increase the availability of legal services for people living with cancer, their families and caregivers.

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## LEUKEMIA AND LYMPHOMA

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### Leukemia and Lymphoma Society

Dedicated to funding blood cancer research, education, patient services and survivorship program for those affected.

### American Lung Association

Lung Cancer (Center for Disease Control)

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## MEDICAL DECISION MAKING

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*(Advance Directives, Living Wills, Healthcare Proxies)*

### Five Wishes

Five Wishes is a comprehensive, person-centered advance care planning program that offers healthcare providers a proven, easy-to-use approach to having effective and compassionate conversations.

### The Conversation Project

Dedicated to helping people talk about their wishes for advance care planning.

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## MELANOMA

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### AIM at Melanoma Foundation

Provides comprehensive online melanoma information for patients and caregiver, supports research, promotes prevention and education for the general public.

# PALLIATIVE CARE RESOURCES

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## MULTIPLE SCLEROSIS

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### [National Multiple Sclerosis Society](#)

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## OVARIAN CANCER

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### SHARE

Providing dedicated, experienced support for women facing breast or ovarian cancer

### [National Ovarian Cancer Coalition](#)

To cure ovarian cancer, advocate for patients, and support survivors.

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## PANCREATIC CANCER

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### [Pancreatic Cancer Action Network](#)

The Pancreatic Cancer Action Network (PanCAN) is dedicated to fighting the world's toughest cancer. In our urgent mission to save lives, we attack pancreatic cancer on all fronts: research, clinical initiatives, patient services and advocacy.

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## PARKINSON'S DISEASE

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### [Michael J. Fox Foundation](#)

Dedicated to finding a cure for Parkinson's disease through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson's today.

### [Parkinson's Foundation](#)

Making life better for people with Parkinson's disease by improving care and by advancing research toward a cure.

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## PEDIATRIC CANCER

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### [Courageous Parents Network](#)

A nonprofit, 501(c)(3) organization, created by parents, for parents of seriously ill children, and by the providers who care for them, with oversight from professional advisory boards.

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## PEDIATRIC PALLIATIVE CARE

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### [National Institute of Nursing Research](#)

The National Institute of Nursing Research (NINR), developed the Palliative Care: Conversations Matter® campaign to increase the use of palliative care for children and teens living with serious illnesses.

### [Get Palliative Care](#) (pediatrics)

# PALLIATIVE CARE RESOURCES

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## PHYSICIANS & PROVIDERS

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### [Palliative Care Provider Directory](#)

Get Palliative Care provides a full directory of all palliative care providers by state and includes hospitals, nursing homes, office/clinics and home care.

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## PROSTATE CANCER

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### [Prostate Cancer](#) (Centers for Disease Control)

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## SICKLE CELL DISEASE

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### [Sickle Cell Disease Association of America](#)

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## SPINAL CORD INJURIES

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### [Spinal Cord Injury Resources by State](#)

A listing of spinal cord injury resources by state. Includes United Spinal Associations, support groups, independent living centers, and state run services.

### [United Spinal Association](#)

United Spinal Association is a nonprofit membership organization dedicated to enhancing the quality of life of all people living with spinal cord injuries and disorders (SCI/D), including veterans, and providing support and information to loved ones, care providers and professionals. Our goal is to provide people living with SCI/D programs and services that maximize their independence and enable them to remain active in their communities.

### [Christopher & Dana Reeve Foundation](#)

We are dedicated to curing spinal cord injury by advancing innovative research and improving quality of life for individuals and families impacted by paralysis. There are many ways to get support, get involved and donate to support the Reeve Foundation mission.

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## STROKE

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### [American Stroke Association](#)

[Healthline](#) (stroke)

# PALLIATIVE CARE RESOURCES

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## SURVIVORSHIP

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### National Coalition for Cancer Survivorship

Survivor-led advocacy organization working to increase access to improved quality care through legislative and public policy change, patient empowerment and education outreach initiatives.

### Annie Appleseed Project

Provides information, education and advocacy about complementary, alternative and integrative cancer care for survivors, family and providers.

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## SUPPORT

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### Patients Rising

Dedicated to providing support and education to those with a chronic and life-threatening illnesses.

### 4th Angel

Provides free and confidential telephone or e-mail support to cancer patients and their caregivers. Trained mentors, who are cancer survivors themselves or caregivers, offer guidance and support.

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## TESTICULAR CANCER

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### Testicular Cancer Foundation

Testicular Cancer Foundation provides education and support to young adult males to raise awareness about testicular cancer, the most commonly diagnosed cancer among males ages 15 – 34.

### Testicular Cancer Awareness Foundation

Raising awareness in the fight against testicular cancer, community support, patient navigation, and financial assistance.

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## TRAUMATIC BRAIN INJURY

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### Bob Woodruff Foundation

An independent, 501(c)3 organization that focuses on helping injured U.S. veterans and service members, as well as their families and caregivers. It was founded by ABC journalist Bob Woodruff and his family after he sustained a life-changing traumatic brain injury while covering the war in Iraq in 2006 that left him in a medically-induced coma for 36 days.

### Brain Injury Association of America

A national 501(c)3 nonprofit organization that focuses on education, training, research, and advocacy. A lot of their efforts are on national TBI advocacy and policy-related work to help improve the quality of life of individuals living with these serious injuries.



# PALLIATIVE CARE RESOURCES

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## VA (VETERANS AFFAIRS)

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[Veterans Guide to Palliative Care](#)

[Veterans Access to Care](#)

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## YOUNG ADULT CANCER

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### [Cancer Care](#)

Professional counseling, facilitated peer support groups, creative workshops and financial assistance for young adults with cancer.

### [Stupid Cancer](#)

Stupid Cancer is a non-profit organization that empowers those affected by young adult cancer through innovative and award-winning programs and services. We are the nation's largest support community for this underserved population and serve as a bullhorn for the young adult cancer movement.

### [Ulman Foundation](#)

Supporting, educating and connecting young adults affected by cancer.