

More Resources

For patients and families at Alford Brain Tumor Center

Brain Tumor Support

Acoustic Neuroma Association

ANA offers information and support for people who have had an acoustic neuroma or other tumors that affect the cranial nerves. ANA was founded by acoustic neuroma patients.

Visit www.anausa.org.

American Brain Tumor Association

ABTA raises funds for brain tumor research and education. Their website offers education and support. Visit

www.abta.org.

The Healing Exchange Brain Trust

T.H.E. Brain Trust runs online support groups and forums on brain tumors for patients, providers, researchers, educators, and caregivers. Visit www.braintrust.org.

Meningioma Mommas

This online support group is for men and women affected by meningiomas. Visit www.meningiomamommas.org.

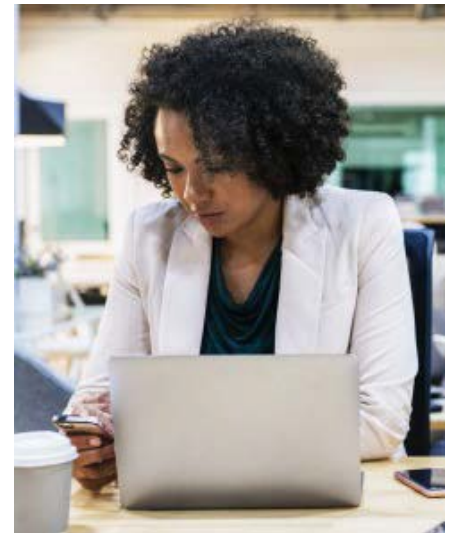
Musella Foundation for Brain Tumor Research and Information

Musella Foundation offers education, emotional and financial support, advocacy, and guidance to brain tumor patients.

Visit www.virtualtrials.com.

Pituitary Network Association

This site provides education and resources for patients, families, and



Talk with your care team if you have any questions about information you read on the internet.

providers. It covers early detection, symptoms, and treatments related to pituitary tumors and disorders. Visit www.pituitary.org.

Scientific Research

Brain Science Foundation

This foundation supports basic and clinical research. Their focus is on meningiomas and other non-malignant primary brain tumors. Visit www.brainsciencefoundation.org.

National Brain Tumor Society

NBTS drives research to find new treatments. They also advocate for policies to meet the needs of the brain tumor community. Visit www.brainumor.org.

Caregiver Resources

Caregiver Action Network

This group helps caregivers take care of their health and well-being. The site gives tips for financial and medical benefits, support groups, respite care, newsletters, and more. Visit <https://caregiveraction.org/about>.

Caregiver Guides

- “Orientation to Caregiving: A Handbook for Family Caregivers of Patients with Brain Tumors” is an excellent resource. Written by the UCSF Osher Center for Integrative Medicine. Visit www.yumpu.com/en/document/read/4973258/a-handbook-for-family-caregivers-of-patients-with-brain-tumors.
- “Caregiver Handbook” is by the American Brain Tumor Association. It provides a helpful introduction to caring for a loved one who has a brain tumor. Visit www.abta.org/publications/caregiver-handbook.

Cancer Care

This site offers stories of help and hope. It includes podcasts for caregivers on subjects ranging from financial aid to managing stress. Visit www.cancercaare.org/tagged/caregiving.

Caregiver Hope

This site offers hope and encouragement for caregivers. Read personal stories about the caregiver journey. See how caregivers found ways to face their fears, gained faith and hope, and learned to embrace life as it changed. Visit www.caregiverhope.com.

Caring Bridge

This site allows you to create a website to share patient updates, photos, and videos. This is a lower-stress way to connect with friends and family who want to help. Visit www.caringbridge.org.

Family Caregiver Alliance National Center on Caregiving

This center offers national, state, and local programs for caregivers who provide long-term care at home. The site contains newsletters, fact sheets, advice, and online support groups. Visit www.caregiver.org.

Lotsa Helping Hands

This site provides online calendars and announcements to help patients and caregivers organize family and friends for tasks. It also provides other resources for caregivers. Visit www.lotsahelpinghands.com.

Well Spouse Association

This site addresses the needs of spouses who are also caregivers. It offers blogs, articles, and events. Visit www.wellspouse.org.

Local Support Groups

Cancer Pathways

This group (which used to be called Gilda's Club of Seattle) offers a local program of social, emotional, and educational support for anyone living with cancer. Friends of cancer patients are also welcome. Visit www.cancerpathways.org.

Cancer Lifeline

This group offers emotional support, resources, classes, and exercise programs for people in all stages of cancer. They welcome patients, survivors, family, friends, co-workers, caregivers, and anyone else affected by cancer. Visit www.cancerlifeline.org.

Cancer Lifeline also offers support by phone. Trained staff and volunteers can listen to your concerns and provide support and

resources. The Cancer Lifeline Phone Line is open Monday through Saturday, 9 a.m. to 9 p.m. Call 206.297.2500.

General Cancer Support

American Cancer Society

ACS offers information about brain tumors, treatments, and managing life with the disease. ACS offers the Health Insurance Assistance Service. Visit www.cancer.org.

American Society of Clinical Oncology

This resource provides direct and accurate information about cancer treatment from oncologists who are experts in their field. Visit www.cancer.net.

Cancer Support Community

This group provides support, education, and hope to all people affected by cancer. They offer some personalized services at no cost. Visit www.cancersupportcommunity.org.

LIVESTRONG Foundation

This site provides information and tools to help people affected by cancer. Visit www.livestrong.org/cancersupport.

Stupid Cancer

The Stupid Cancer website connects young people with cancer to peers and age-appropriate resources. Their mission is “to empower teens and young adults affected by cancer by ending isolation and building community.” The site includes advocacy, research, support, outreach, awareness, mobile health (using smartphones, tablets, and other devices), and social media. Visit www.stupidcancer.org.

Triage Cancer

This site provides education and resources on cancer survivorship issues to survivors, caregivers, advocates, and healthcare providers. They offer educational events, cancer survivorship webinars, and teaching materials. Visit www.TriageCancer.org.

Legal Resources

Cancer Legal Resource Center

This center provides free information for legal issues relating to cancer, including health insurance, employment rights, estate planning, disability benefits, living wills, and durable power of attorney. Visit <https://disabilityrightslegalcenter.org/cancer-legal-resource-center>.

LawHelp

This site helps people with low and moderate incomes find free legal aid programs in their communities. It answers questions about legal rights and can help with legal problems. Visit www.lawhelp.org.

Washington State Long-Term Care Ombudsman

This program advocates for residents of nursing homes, adult family homes, and assisted living facilities. Staff members investigate and resolve complaints made by or on behalf of people who are living in these care facilities. Visit www.waombudsman.org.

National Cancer Legal Services Network

This coalition of legal service providers offers free legal service programs to people affected by cancer. Visit <https://tragecancer.org/national-cancer-legal-services-network>.

Patient Advocate Foundation

This foundation helps patients with issues such as access to healthcare, insurance, and employment; disability benefits; and co-payment aid. Their handouts include “The Managed Care Answer Guide” and “Your Guide to the Appeals Process.” Visit www.patientadvocate.org.

Free Phone Apps

- **Cancer.net** by the *American Society of Clinical Oncology*. This app lets users save information about prescriptions, including photos of labels and bottles. It has a symptoms tracker, sample questions to ask your doctor, and guides to 120 types of cancer.
- **Pocket Cancer Care Guide** by the *National Coalition for Cancer Survivorship*. This app lets users record answers from doctors and nurses and links appointments to a calendar. It includes definitions of medical terms.

- **My Cancer Manager** by *Cancer Support Community*: This mobile screening app provides patients and caregivers with a unique set of tools to address their physical, social, and emotional concerns related to living with cancer.
- **Create to Heal** by the *Women Wings Create to Heal Program*: This app uses the healing power of creativity to relieve stress during long treatment and recovery hours. Use the app to play music and explore art, color, meditation, and creative writing tools.
- **My PearlPoint Cancer Side Effects Helper** by *PearlPoint Cancer Support*: This app helps users learn about what is causing side effects and how to ease discomfort.
- **Chemo Brain Doc Notes** by a cancer patient and the *CrowdCare Foundation Inc.*: This app helps you organize and manage treatment information by recording answers from doctors and nurses.
- **Med Helper** is a medicine compliance and tracking app that you can use to set reminders for complex medicine schedules. It also has a notes feature that records dates, time-stamps notes, and can be used to track side effects and symptoms. Extra features include medicine inventory tracking.
- **Stress Free Now** by the *Cleveland Clinic*. This app helps patients and caregivers lower stress by helping them to become truly present.
- **StoryCorps** from the nonprofit organization *StoryCorps*: The app has given 100,000 people the chance to record interviews about their lives, pass wisdom from one generation to the next, and leave a legacy for the future. It provides interview questions and lets people make a recording using their own phone. They can then upload their story to the StoryCorps website to be shared with friends and family.

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Alvord Brain Tumor Center:
206.598.2282