Survivorship Resources



Learn about support groups, educational resources, financial aid and more for survivors of childhood adolescent and young adult cancer and bone marrow transplant. Please note: we do not endorse and are not responsible for the information or services on this list.

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General survivorship



Doernbecher Cancer Survivorship

Website about our long-term follow-up clinic, resource and scholarship lists, events, link to our Facebook page, and more.

www.ohsu.edu/doernbecher/doernbecher-cancer-survivorship-program

Children's Oncology Group Family Handbook

For new diagnoses through survivorship. The COG KidsCare App contains the entire COG Family Handbook and New Diagnosis Guide, plus journaling, appointment tracking, and more. Available on the App Store or Google Play.

childrensoncologygroup.org/index.php/family-handbook

Book: Childhood Cancer Survivors

A practical guide to your future (Keene, Hobbie, Ruccione). www.childhoodcancerguides.org/our-books/childhood-cancer-survivors

Pediatric Brain Tumor Foundation

PBTF offers a survivorship guidebook, webinars, support groups and more for families impacted by childhood brain tumors.

http://www.curethekids.org/family-resources/

BMT Info Net

Connection services, support groups, video library and educational resources for bone marrow transplant patients and survivors.

www.bmtinfonet.org

Children's Brain Tumor Foundation

Virtual chats, support groups and educational events for brain tumor survivors and caregivers. https://cbtf.org/

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General survivorship



Be The Match

Provides support, information and resources for transplant patients, caregivers and families. https://bethematch.org/patients-and-families/life-after-transplant/

St. Jude's Together

Website includes a "Life after Cancer" section where survivors and families can learn to manage school and work issues. Also, learn ways to stay healthy, both physically and emotionally. together.stjude.org/en-us/life-after-cancer

Neuroblastoma Info

Learn all about after treatment, what happens next and when. www.neuroblastoma-info.com/after-treatment/whats-next



Teens and young adults



Teens & 20s

Website for teens and young adults with a cancer experience.

https://together.stjude.org/en-us/teensand20s.html

Stupid Cancer

Young adult cancer resources and support.

www.stupidcancer.org

Cactus Cancer Society

Online wellness programs and support from other young adult survivors.

cactuscancer.org

CancerCon

Yearly conference for young adult cancer survivors.

stupidcancer.org/events/cancercon

Project Koru

Free retreats in Hawaii and Oregon (transportation not included), workshops and virtual support groups to help cancer survivors diagnosed at ages 18-39.

www.projectkoru.org

Epic Experience

Free week-long outdoor camps in Colorado for anyone age 18+ who was diagnosed with cancer at any time in their lives.

www.epicexperience.org

First Descents

Multi-day adventure program for young adult cancer survivors. Free programs located across the United States (transportation not included but travel scholarships are available). For young adults ages 18-45.

firstdescents.org

True North Treks

Outdoor adventures across the United States for teen and young adult cancer survivors ages 18-39 and caregivers.

www.truenorthtreks.org

Camp Mak-A-Dream

Montana summer camps and retreats for teens and young adults with cancer experience and their family members (transportation not included).

www.campdream.org



Teens and young adults



LEAP

Free whitewater kayaking programs for teen patients at Doernbecher Children's Hospital. On the Lower Salmon River in Idaho. Ask a Doernbecher oncology social worker for more information.

www.leapadventure.org/partners

National LGBTQ+ Cancer Network

Offers resources and virtual peer-support groups for LGBTQ+ individuals who have or have had cancer.

https://cancer-network.org/

Escape AYAC

Serves LGBTQIA+ teens and young adults through virtual meetups, events, writing groups, and resources.

https://www.escapeayac.org/

Elephants and Tea

Social Community Programs, Informative Programs, Caregiver Programs, Support Groups, Conferences, and events designed specifically for the LGBTQIA+ community.

https://elephantsandtea.com/programs-and-events/

Lets Take Charge

Robust list of educational and financial resources related to fertility after cancer treatment www.letstakecharge.org/resources

Life with Cancer Classes

Virtual movement and educational classes (classes run by mental health professional only open to people on east coast due to licensing restrictions).

https://events.lifewithcancer.org/class_calendar_month.php



Educational resources



Booklet: Learning & Living with Cancer

Advocating for your child's educational needs.

https://www.lls.org/booklet/learning-living-cancer

Educational Issues Following Treatment for Childhood Cancer

www.survivorshipguidelines.org/pdf/EducationalIssues.pdf

The National Grace Foundation

College admissions and financial aid counseling and advocacy for young cancer survivors and their families.

graceamerica.org/GraceFoundation/services

U.S. Department of Education

How students with disabilities can prepare for college.

www2.ed.gov/about/offices/list/ocr/transition.html



Financial and career help



Triage Cancer

Free events, materials and resources to learn about legal and financial issues that may impact survivors and their families.

triagecancer.org

Family Reach

Free financial planning services to help families dealing with cancer. Must be in treatment or less than 1 year since the end of treatment.

familyreach.org/ftp

Samfund Living Grant

Grants for young adults after cancer.

www.thesamfund.org/get-help/grants

Leukemia and Lymphoma Society

Help for healthcare costs that include long-term follow-up care.

www.lls.org/support/financial-support

Cancer and Careers

Helps people with cancer and survivors to thrive in their workplace.

www.cancerandcareers.org

Triage Cancer Finances Toolkit

How young adults can find out about disability benefits, health insurance, employment, medical bills and managing money.

triagecancer.org/cancer-finances

Vocational Rehabilitation

Free help for people with disabilities to get and keep a job.

Oregon: www.oregon.gov/dhs/employment/VR/Pages/index.aspx

Washington: www.dshs.wa.gov/dvr

US Government Office of Equal Opportunity

How to ask for workplace accommodations due to disability.

www.eeoc.gov/laws/guidance/fact-sheet-disability-discrimination



Disabilities



Doernbecher Lifespan Transition Clinic

For ages 14-21 with disabilities. Help with reaching goals as you become an adult. Ask your doctor or social worker for a referral.

www.ohsu.edu/university-center-excellence-development-disability/lifespantransition-clinic

Social Security Disability Benefits

Learn about the benefits, eligibility and the application process. www.ssa.gov/ssi/text-apply-ussi.htm

www.ssa.gov/benefits/disability

Oregon and Washington's Guide to Accessible, Inclusive, and Adaptive Activities

List of sports, attractions, entertainment and more.

madmagz.com/magazine/1081928#

Oregon Family to Family Health Center

Helping kids and families with special health needs to navigate health care systems.

www.ohsu.edu/oregon-family-to-family-health-information-center

Camp and recreation list

www.ohsu.edu/oregon-family-to-family-health-information-center/sports-and-recreation

Consider Camp List

For children, families and young adults.

www.ohsu.edu/sites/default/files/2019-05/SummerCampListLiveLinks.pdf

Oregon Office of Developmental Disabilities

Offers in-home and residential supports, and service coordination to eligible children, adults, and families

www.oregon.gov/dhs/SENIORS-DISABILITIES/DD/Pages/eligibility.aspx

Washington State Developmental Disabilities Administration

For children, families and young adults.

www.dshs.wa.gov/dda/consumers-and-families/eligibility

Lifecourse Supported Decision Making Tools

www.lifecoursetools.com/lifecourse-library/exploring-the-life-domains/supported-decision-making/

Supported Decision making & future planning for people experiencing intellectual disability

https://thearcoregon.org/gaps/future-planning/

ACLU Supported Decision Making Resource Library

www.aclu.org/other/supported-decision-making-resource-library



Activities and outdoor camps



Camp Agape

Free summer overnight camp in NW Oregon for families impacted by childhood cancer. campagapepdx.com

Camp Korey

Free overnight camps in Washington for children and families impacted by various health conditions

www.campkorey.org

Camp Mak-A-Dream

Free in person Montana summer camps for kids, families, and young adults with a cancer experience (transportation not included).

www.campdream.org

Camp Millennium

Free summer overnight camp in Southern Oregon for children with a cancer experience and their siblings.

campmillennium.org

Candlelighters Family Camp

Free summer overnight camp in Eugene, Oregon for families affected by childhood cancer. candlelightersoregon.org/connecting-families-with-childhood-cancer

Every Kid Sports

Youth sports grant to help cover registration fees for children ages 4-18 in Oregon who are currently enrolled in Medicaid, SNAP or WIC.

https://everykidsports.org/every-kid-sports-pass/

Pablove Shutterbugs

Free virtual photography courses for ages 6-18, equipment is provided at no cost. www.pablove.org/student-application/

Roundup River Ranch

Free in person, online camps and activity boxes by mail for kids in Colorado with serious medical conditions and their families (assistance with transportation available). roundupriverranch.org

Ukandu

Free overnight camps in NW Oregon for kids and families impacted by childhood cancer. https://ukandu.org/



Support groups and peer support



CoHeals

Free app to connect with other people or families impacted by childhood cancer. coheals.com

Young Adult Writing Group at OHSU

For people ages 15 – 39 with a cancer experience. Not a workshop to learn to write. No writing experience needed.

To register, email dawnrenethompson@gmail.com www.ohsu.edu/knight-cancer-institute/cancer-education-and-support-groups

The Luminaries

A Candlelighters of Oregon program for teens with a cancer experience and their siblings ages 13 – 19 to connect with one another.

candlelightersoregon.org/connecting-families-with-childhood-cancer

Candlelighters of Oregon Parent Support Group

Connect with other parents who understand what it's like to have a child with cancer. candlelightersoregon.org/connecting-families-with-childhood-cancer

OHSU Mindfulness-Based Stress Reduction

Mindfulness classes for patients, survivors and caregivers. People who finish the classes have less pain, fatigue and anxiety (may have cost associated).

www.ohsu.edu/mindfulness

Children's Cancer Association

Fun programs for kids and families in Oregon.

joyrx.org

The Children's Brain Tumor Foundation

Robust virtual support group offerings, and art workshops for survivors, siblings and caregivers

https://cbtf.org/

Imerman Angels

Mentorship and support for people with a cancer experience.

imermanangels.org/get-support



Mental health and emotions



Emotions after childhood cancer

www.survivorshipguidelines.org/pdf/healthlinks/English/emotional_issues_Eng.pdf

National Children's Cancer Society

Emotions for survivors.

www.thenccs.org/emotions

How to find the right therapist

www.realsimple.com/health/mind-mood/emotional-health/how-to-find-a-therapist

Psychology Today Therapist Search Engine

Search for a therapist by insurance type, issue, location, etc.

www.psychologytoday.com/us/therapists

988 Suicide & Crisis Lifeline

When people call, text, or chat 988, they will be connected to trained counselors that are part of the existing Lifeline network. These trained counselors will listen, understand how their problems are affecting them, provide support, and connect them to resources if necessary. https://988lifeline.org/

Lines for Life Youthline

24/7 teen-to-teen helpline. Crisis support by call, text and chat. Answered by teens daily 4-10 p.m. (and by adults at all other times).

Call: 877-968-8491

Text: teen2teen to 839863 www.oregonyouthline.org



Health, nutrition and wellness



Oregon Food Bank Food Finder

Find food pantries and pick up sites near you.

foodfinder.oregonfoodbank.org

Parks and Recreation

Classes, gym memberships and pool passes.

Financial help available.

www.portland.gov/parks/recreation

Survivorship Guidelines

Learn about diet, exercise, skin health, dental health and more.

survivorshipguidelines.org

Oregon State University's Food Hero

Quick, tasty, healthy recipes and helpful tips.

foodhero.org

The Academy of Nutrition and Dietetics

Nutrition information for the whole family.

www.eatright.org

Good and Cheap, Eat Well on \$4 a day

Free cookbook.

books.leannebrown.com/good-and-cheap.pdf

Nemours TeensHealth

Learn about nutrition, physical and emotional health, safety and more.

kidshealth.org/en/teens

The American Academy of Pediatrics Parenting

Learn about growth and development, safety and prevention, physical and emotional health, and more.

www.healthychildren.org

The Centers for Disease Control Vaccines

Easy-to-read immunization schedules for all ages.

www.cdc.gov/vaccines/schedules

Oregon Pain Education Toolkit

Pain management education for patients about how they can improve their health and better manage their pain.

www.oregonpainguidance.org/paineducationtoolkit/



Transition to adulthood in healthcare



Family readiness toolkit and transition quizes for teens and caregiver

www.gottransition.org/resource/?hct-family-toolkit www.gottransition.org/youth-and-young-adults/hct-quiz.cfm www.gottransition.org/parents-caregivers/hct-quiz.cfm

Triage Cancer Checklist for turning 18

https://triagecancer.org/quick-guides/child-turns-18

