

Childhood Cancer Survivorship Resources

***This list is subject to change and is not an exhaustive list. Providing references to other organizations or links to other websites does not imply that OHSU endorses the information or services provided by them. Those organizations and/or websites are responsible solely for the information they provide. Listing of resources and websites is for informational purposes only.**

General survivorship resources:

Doernbecher Cancer Survivorship website: for information about our long-term follow-up clinic, resource and scholarship lists, upcoming events, link to our Facebook page, and more:
<https://www.ohsu.edu/doernbecher/doernbecher-cancer-survivorship-program>

Pediatric Brain Tumor Foundation Survivorship Guidebook:
https://curethekids.formstack.com/forms/survivorship_resource_guidebook

Children's Oncology Group Family Handbook (for new diagnoses through survivorship):
<https://childrensoncologygroup.org/index.php/family-handbook>

BMT Info Net: Various resources for survivors and caregivers: <https://www.bmtinfonet.org/>

Book: Childhood Cancer Survivors: A practical guide to your future (Keene, Hobbie, Ruccione):
<https://www.childhoodcancerguides.org/our-books/childhood-cancer-survivors/>

Teens and young adults:

Stupid Cancer is a non-profit organization that provides young adult cancer resources and supports:
<http://www.stupidcancer.org/>

Lacuna Loft provides online wellness support programs, lifestyle encouragement, and a peer support community for young adults with a cancer experience: <https://lacunaloft.org/>

CancerCon: an annual conference for young adult cancer survivors:
<https://stupidcancer.org/events/cancercon/>

Children's Hospital of Philadelphia Survivorship Manual for teens and young adult survivors:
<https://media.chop.edu/data/files/pdfs/oncology-aya-survivorship-manual.pdf>

Project Koru offers camps, retreats, and workshops to help cancer survivors diagnosed between ages 18-39: <https://www.projectkoru.org/why-we-exist/>

Epic Experience offers free week-long outdoor camp experiences for individuals (ages 18+) who have been diagnosed with cancer at any time in their lives: <https://www.epicexperience.org/>

First Descents is a multi-day adventure program for young adult cancer survivors:
<https://firstdescents.org/>

True North Treks offers outdoor adventures for teen and young adult cancer survivors and caregivers:
<http://www.truenorthtreks.org/>

Camp Mak-A-Dream in Montana offers summer camps and retreat experiences to teens and young adults with a cancer experience: <https://www.campdream.org>

LEAP offers free whitewater kayaking programs for teen patients at Doernbecher, on the Lower Salmon River in Idaho. LEAP provides patients the opportunity to process their experience outside the hospital environment, build community and connections with other kids living with illness, and be empowered by their physical capabilities. Speak with a Doernbecher oncology social worker for more information:
<http://www.leapadventure.org/partners>

Educational Resources:

Learning & Living with Cancer Booklet: Advocating for your child's educational needs:
https://www.livestrong.org/sites/default/files/Learning_Living_with_Cancer.pdf

Educational Issues Following Treatment for Childhood Cancer with associated supports/resources:
<http://www.survivorshipguidelines.org/pdf/EducationalIssues.pdf>

SamFund Webinar about college financial assistance for childhood cancer survivors:
<https://www.youtube.com/watch?v=lnKvYZ11Cho>

The National Grace Foundation offers college admissions and financial aid counseling and advocacy to young cancer survivors and their families: <http://graceamerica.org/GraceFoundation/services/>

Financial aid information and scholarships for individuals experiencing disability:
<https://www.onlineschools.org/financial-aid/disabilities/>

Scholarships for college textbooks for childhood cancer survivors: Scholarships of up to \$1,000 per year, renewable for up to five years, are offered to cover textbook expenses for individuals being treated for or who are survivors of childhood cancer: www.survivorvision.org

Students with Disabilities Preparing for Postsecondary Education-Know your Rights and Responsibilities:
<https://www2.ed.gov/about/offices/list/ocr/transition.html>

Financial & Career Assistance

Triage Cancer provides education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers, through free events, materials, and resources:
<https://trriagecancer.org/>

Family Reach provides free financial planning services and resources to help patients and families overcome the financial side effects of a cancer diagnosis. Must be in active treatment or within one year of the end of treatment to qualify for services: <https://familyreach.org/ftp/>

Samfund Living Grant for young adults after cancer: <http://www.thesamfund.org/get-help/grants/>

Leukemia and Lymphoma Society helps with healthcare related costs that include long-term follow up care: <http://www.lls.org/support/financial-support>

Cancer and Careers empowers and educates people with cancer and survivors to thrive in their workplace, by providing expert advice, interactive tools and educational events: <https://www.cancerandcareers.org/en>

Samfund & Triage Cancer Finances Toolkit for young adults with a cancer experience. Gives in-depth information about disability benefits, health insurance, employment, medical bills, and managing money: <https://cancerfinances.org/toolkit/>

Vocational Rehabilitation is available to individuals experiencing barriers to employment and provides training and support to find a sustainable career in every county across the nation. Services are free of charge: <https://www.oregon.gov/dhs/employment/VR/Pages/index.aspx>

US Gov Office of Equal Opportunity website with info regarding requesting reasonable workplace accommodations due to a medical condition: https://www.eeoc.gov/eeoc/internal/reasonable_accommodation.cfm

Individuals and families experiencing disability:

Doernbecher Lifespan Transition Clinic is designed for youth ages 14-21 who are experiencing disability related to cancer treatments and mental health disorders. Youth and their families will be assisted to develop a transition action plan that provides resources and supports to help meet their goals as they transition into adulthood. Areas covered include physical health & wellness, mental health and wellness, community participation, and supported-decision making for their future. Discuss a referral with your doctor or social worker: <https://www.ohsu.edu/university-center-excellence-development-disability/lifespan-transition-clinic>

How to apply for social security disability benefits: <https://www.ssa.gov/ssi/text-apply-ussi.htm>

Information about disability benefits and the disability process: <https://www.ssa.gov/benefits/disability/>

Oregon and Washington's Guide to Accessible, Inclusive, and Adaptive Activities: Fun for Everyone: <https://madmagz.com/magazine/1081928#/>

The ARC: Comprehensive list of community resources for individuals and families experiencing developmental disabilities: <https://thearcoregon.org/resources/community-resources/>

Adaptive Sports NW for children and adults experiencing disability: <http://www.adaptivesportsnw.org>

Oregon Adaptive Sports (OAS) in Deschutes county/Bend area offers adaptive sports lessons/outings for youth and adults experiencing disability. Scholarships are available: <https://oregonadaptivesports.org/sports/register/>

Oregon Family to Family Health Center supports families and caregivers of children with special health needs to navigate the complex health care systems. This website houses hundreds of resources for parents, grandparents, teens, and young adults: <https://www.ohsu.edu/oregon-family-to-family-health-information-center>

The ARC: Information about legal guardianship and less restrictive alternatives such as supported decision making: <https://thearcoregon.org/gaps/guardianship/>

Outdoor camps for survivors, siblings, & families:

Ukandu: The mission of UKANDU is to bring joy, hope, and connection to communities impacted by childhood and adolescent cancer through free virtual and in person camp-like experiences in NW Oregon: <https://campukandu.org/come-to-camp/>

Camp Agape: a family residential camp in Oregon that offers a summer camp experience to cancer-afflicted children and their families: <https://campagapepdx.com/>

Camp Millennium: a free summer camp for children with a cancer experience and their siblings outside of Roseburg, Oregon: <https://campmillennium.org/>

Candlelighters Family Camp: a free three-day summer camp for families affected by childhood cancer who are currently undergoing treatment, in remission, or bereaved: <https://www.candlelightersoregon.org/index.php/programs/family-camp>

Camp Korey in Washington empowers children living with serious medical conditions and their families through year-round, life-changing experiences, always free of charge: <https://www.campkorey.org/>

Roundup River Ranch in Colorado offers old-fashioned, pure fun camp experiences for children with serious illnesses and their families. Children must be within three years of active treatment and/or currently experiencing the challenges of a chronic or serious condition: <https://roundupriverranch.org/>

Camp Mak-A-Dream in Montana offers summer camps and retreat experiences to children, teens, young adults, families, and parents/caregivers with a cancer experience: <https://www.campdream.org>

LEAP offers free whitewater kayaking programs for teen patients and siblings of Doernbecher patients, on the Lower Salmon River in Idaho. LEAP's sibling participants have the unique opportunity to step outside of their family roles, connect with kids who are dealing with similar challenges, and reflect on their strengths and capacities. Speak with a Doernbecher oncology social worker for more information: <http://www.leapadventure.org/>

Support groups & peer support for survivors, siblings, & parents/caregivers:

CoHeals: a free app for connecting and building relationships among families impacted by pediatric cancer: <https://coheals.com/>

Young Adult Writing Group at OHSU. This weekly group is for people ages 15 to 39. This is not a workshop where you will learn to write, and you do not need writing experience to participate. Email facilitator Dawn Thompson to register: dawnrenethompson@gmail.com
<https://www.ohsu.edu/knight-cancer-institute/support-groups-and-classes-cancer>

The Luminaries: a Candlelighters program for teens ages 13-19 who have experienced cancer (and/or their teen siblings) to connect and support one another through social connections and service projects.

For more information email: Lisa@candlelightersoregon.org

<https://www.candlelightersoregon.org/index.php/family-activity/teen-programs>

Candlelighters Parent Support Group: Connecting with other parents who understand what having a child diagnosed with cancer is helpful. Support group meetings facilitated by Dr. Marianne Kabour:

<https://www.candlelightersoregon.org/index.php/programs/resources>

OHSU Mindfulness Based Stress Reduction (MBSR) 8-week course and drop in groups for cancer patients, survivors, and caregivers. Research shows that cancer patients who complete the course report reductions in pain, fatigue, anxiety and sleep disturbance and an overall increase in quality of life. Classes include mindfulness instruction and practice, group discussions and educational presentations on the relationships between mindfulness, stress, and wellness:

<https://www.ohsu.edu/xd/health/services/mindfulness/>

Children's Cancer Association offers joy-centric programs (music, mentorship, and nature) to create feel-good moments for patients: <https://joyrx.org/>

Northwest Sarcoma Foundation Virtual Casual Chat for Teens: Join teen sarcoma patients and survivors to discuss sarcoma with those who understand. <https://www.classy.org/event/casual-chat-for-teens-ages-13-18/e328098>

The Children's Brain Tumor Foundation offers a variety of virtual support groups and chats for all members of the family including parents, young pre-teen and teen support, young adults, and siblings:

https://childrensbraintumorfoundation.networkforgood.com/events/28607-children-s-brain-tumor-foundation-support-groups?utm_campaign=dms_email_blast_1145685

Mental Health & Emotions

Emotions after childhood cancer:

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

Information for survivors on emotions (National Children's Cancer Society):

<https://www.thenccs.org/emotions/>

Psychology Today Therapist Search Engine is a tool that can be used search for a therapist by insurance type, group or individual therapy, issue, geographical area, etc:

<https://www.psychologytoday.com/us/therapists>

24/7 National Suicide Prevention Lifeline Hotline and online chat feature 1-800-273-TALK (8255):

[\(suicidepreventionlifeline.org\)](http://lifeline (suicidepreventionlifeline.org))

Lines for Life Youthline - Call 877-968-8491 or text teen2teen to 839863: <https://oregonyouthline.org/>

Oregon mental health crisis hotlines by county:

<https://www.oregon.gov/oha/ph/PreventionWellness/SafeLiving/SuicidePrevention/Pages/crisislines.aspx>

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Health, Nutrition, and Wellness

Oregon Food Bank Food Finder: locate food pantries and pick up sites near you:

<https://foodfinder.oregonfoodbank.org/>

Free summer fitness pass for teens ages 15-18: <https://www.planetfitness.com/TeenSummerChallenge>

Parks and Recreation facilities in counties across the state often offer financial aid for classes, gym memberships, and pool passes: <https://www.portland.gov/parks/recreation>

Survivorship Guidelines patient education links (diet and exercise, skin health, dental health and more): <http://survivorshipguidelines.org/>

Oregon State University's Food Hero, a site for quick, tasty, healthy recipes and helpful tips:

<https://www.candlelightersoregon.org/index.php/programs/resources>

The Academy of Nutrition and Dietetics provides reliable and evidence-based nutrition information for the whole family: <https://www.eatright.org/>

Nemours TeensHealth provides information about nutrition, physical and emotional health, safety and more: <https://kidshealth.org/en/teens/?WT.ac=t2t>

The American Academy of Pediatrics Parenting Website offers information and resources about growth and development, safety and prevention, physical and emotional health and more:

<https://www.healthychildren.org/English/Pages/default.aspx>

The Centers for Disease Control website offers easy-to-read immunization schedules for all age groups:

<https://www.cdc.gov/vaccines/schedules/index.html>

Transition to Adulthood in Healthcare

Family Readiness Toolkit: <https://www.gottransition.org/resource/?hct-family-toolkit>

A healthcare transition quiz for teens: <https://www.gottransition.org/youth-and-young-adults/hct-quiz.cfm>

A sample transition readiness checklist for teens: <https://www.gottransition.org/6ce/?leaving-readiness-assessment-youth>