Psychosocial health in pediatric cancer survivors

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Pediatric Moving Beyond Cancer to Wellness

Hosted by the Fred Hutch and Seattle Children's Survivorship Program





Overview

- 1. Overview of research on psychosocial health in pediatric cancer survivors, caregivers, and siblings
- 2. Strategies and recommendations for supporting survivors & their families
- 3. Resources how/where to find more help
 - Patients, caregivers, siblings
 - Cancer and Blood Disorders Center
 - Seattle Children's Hospital
 - Community
 - Online resources



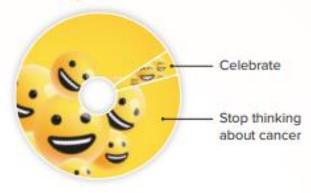
4. Q&A

Psychosocial health in pediatric cancer survivors



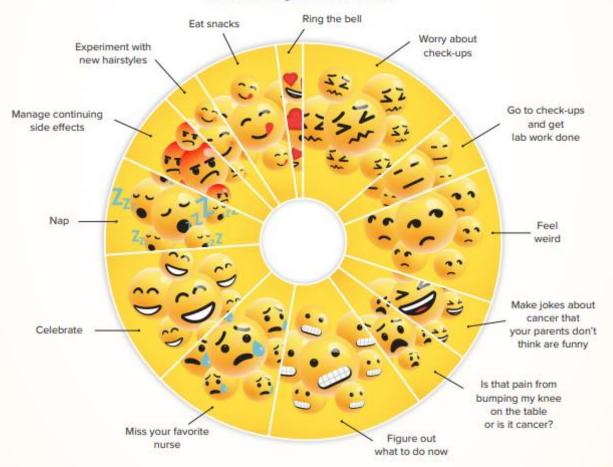
AFTER TREATMENT

What People Think You Do After Finishing Cancer Treatment





What You Actually Do After Finishing Cancer Treatment





Adjustment to diagnosis and treatment

- New diagnosis
- Stressors and demands of treatment
- Unexpected or unplanned events
- Impacts on multiple areas of life
 - Family, friends, relationships, school, work, hobbies, energy, activity, sleep, eating, physical appearance, mood, emotions, independence, priorities, etc.



Adjustment to life after cancer...

Getting back to "normal"

- How do you fit back in with your family?
- How do you fit back in with your friends?
- How do you go back to school?
- How do you regain independence and build more independence?
- How do you go back to not being in or at the hospital all the time?
- How do you build health behaviors and life habits?
- How do you find the "right" balance of paying attention to your body/symptoms without being overly hypervigilant and stressed about "normal" body changes/feelings
- How do you process everything you've been through?



Childhood cancer survivors are resilient

- Survivors are generally resilient and show positive adjustment
- They may experience positive outcomes related to enhanced coping abilities
 - Post-traumatic growth
 - Positive changes in self, relationships, and future plans
- Majority (85%) of adolescent cancer survivors report at least 1 positive consequence of having had cancer
- 32% reported 4+ positive changes



At risk for psychosocial late effects

- <u>Mental health</u>: psychological distress, depression, anxiety, post traumatic stress symptoms, self-esteem, behavior
- <u>Social</u>: peer relationships, family relationships, intimate and marital relationships, peer support
- Health-related: health behaviors, risky health behaviors
- Academic and vocational: school, educational attainment, employment
- Cognitive late effects
- Financial stability



Challenges in survivorship

- Psychosocial health is often affected by physical health
- Continually navigating adjustment across multiple life domains
- Fear of relapse, scanxiety, survivor's guilt
- Sometimes finishing treatment is harder than being on treatment
- "Now what...?"



Parents & caregivers

- Parents and caregivers are both resilient and deeply affected by a child's cancer diagnosis
- Majority of parents report positive outcomes from cancer experience
- Distress decreases over time for many parents
- However, some parents experience greater distress, worry, posttraumatic stress symptoms (PTSS), strains in family relationships, financial, and work difficulties
 - Severe PTSS in 10-44% of parents



Siblings

- Generally psychologically healthy, show resilience or enhanced functioning
- Some are at risk for emotional and behavioral difficulties
 - E.g., anxiety, depression, posttraumatic symptoms, academic and social disruptions
- Difficulties more common earlier on and tend to improve over time
- Some siblings are at risk for long-term psychosocial difficulties



Strategies & recommendations to support psychosocial health





What can help with overall adjustment

- Expect that adjustment will take some time
- Give yourselves time and grace to find your footing again
- Acknowledge, validate, and normalize challenges and difficult emotions
- Facilitate adjustment with conversation and preparation
 - Spending time with a few friends prior to larger social gatherings
 - Going to school to meet with teachers prior to returning to school



What can help with overall adjustment

- As health improves, set developmentally appropriate expectations with graded support as needed
 - Independence (e.g., sleeping, going places, ordering for self, hygiene behaviors, etc.)
 - Household duties (e.g., chores, behavior, participation, etc.)
 - School
- Do fun things ©
 - Social activities
 - Active activities
 - Camps!
- Seek additional help and support when needed; access available resources



Increase health literacy

- Get familiar with the "End of Therapy" summary, stay in touch with your survivorship team, keep notes organized
- Encourage developmentally appropriate independence in <u>transitioning knowledge</u> from parent to child
 - For children who were treated when they were young, develop a concise narrative that includes treatment essentials
 - Encourage children to learn the names of their diagnoses, medications, and procedures



Increase health literacy

- Encourage developmentally appropriate independence
 - Monitoring health
 - Scheduling follow-up visits
 - Refilling prescriptions, etc.
- Regular discussion of health promotion and risk behaviors
 - E.g., use sunscreen, eat well, exercise, avoid drugs/alcohol, safe sex practices, etc.
 - Recommended surveillance/follow up, such as labs, ECHO, etc.



http://www.gottransition.org

When to consider mental health support

- Persistent sadness or anxiety
- Persistent difficulty integrating with friends and peers
- Distress impacts functioning
- Risk behaviors
- Significant effects of treatment, requiring more extensive support
 - Academic issues
 - Mobility or sensory impacts
 - Medical complications requiring ongoing management
 - Transition support to address academic, occupational, and independent living needs



When discussing mental health services...

Common misconceptions

- I don't want to be forced to talk about this.
- I don't want to be analyzed or judged.
- The therapist will fix this.
- Therapy won't help.
- Therapy is not for me.
- What did I say that made my doctor place the referral? Do they think I'm crazy?

Helpful reframe

- It is <u>normal</u> for people who have been through extremely stressful circumstances to talk to a mental health provider.
- We can <u>all learn</u> new ways of coping, communicating, working together, etc.
- A therapist is like a "talking doctor."
- A therapist can teach me specific skills to make life easier, less uncomfortable.
- A therapist can help me think through and "process" my thoughts and feelings about what happened or what is happening.
- I don't have to protect mental health providers from my sad or worried feelings.



Psychosocial supports and resources

- Patients, Caregivers, Siblings
- CBDC, Seattle Children's, Community, Online



Annual survivorship visit

- Meeting with survivorship social worker, Brianna Foley
- Psychosocial screening with psychology advanced practicum student
- Mood, anxiety, school/work, peer and social issues, health behaviors, etc.
- Recommendations & referrals



CBDC Psychology Team

- Joanna Patten, PsyD Clinical Director
- Sherilynn Chan, PhD
- Stacey Haynes, PhD
- Stella Fausto, MSW, LICSW
- Gretchen VonHeeder-Phillips, MSW, LICSW
- Practicum students











Behavioral Health Groups

- High School Cancer Group
- Adolescent and Young Adult (AYA) Cancer Group
- (Middle School Life After Cancer Group on pause)



- For patients on or off treatment for cancer or brain tumor, or who received a BMT
- 8 virtual group sessions
- Fall (Sept-Oct) and Spring (May-June)



PE2523 AYA Cancer Group (seattlechildrens.org)
PE3564 High School Cancer Group (seattlechildrens.org)

Art Therapy Groups

Art and Heart Space Virtual Art Therapy group

- <u>Time:</u> Mondays 4-5pm
- Date: 10/2/23 11/20/23
- For cancer care patients and siblings (ages 8 to 13)



Ink About It Virtual Art Therapy group

- Time: Mondays 5:15-6:15pm
- Date: 10/2/23 11/20/23
- For siblings of cancer care patients (ages 8 to 13)





Helena Hillinga Haas, 206-987-6724

Link to sign up: https://forms.office.com/r/EHP9BRnk1V



CANCER SURVIVORSHIP PHOTOVOICE PROJECT

The goal of this group is to come together and use photography as self expression. The group will choose topics related to their cancer journeys and will be asked to photograph images that resonate with each topic. The Photovoice Project is an empowering and reflective process that gives a voice to the experiences of Seattle Children's cancer survivors. No photography experience is needed.

Participants will use the cameras on their phones. No cost to participate.

Interested in joining? Questions? Call or e-mail Brianna Foley (Cancer Survivorship Social Worker) at 206-987-4765 or brianna.foley@seattlechildrens.org.

Located in person at Seattle Children's Main Hospital Campus

6 week commitment

Ages 16 +

No photography experience needed

Food and refreshments provided

Group begins November 7th at 6:30pm



Camps

Specialty/ Program	Location	Group Name	Patient/ Sibling/ Caregiver/ Parent	Eligibility	Age Range	Day/Time	Next Group Dates	# of Sessions	How do I get into the group?	Link to flyer	Contact Person	Status	# of Participant s Allowed in Group	PT Location at time of service (instate/out of state)	# of Patients Currently Enrolled	Billing (free/billed to insurance)	Camp Description
Camp	Varies	Camp Koru	Patient	Patient OFF-treatment	18-39 уо	Determined by applicant	Determined by applicant	One week	Online Application	https://www.projectkoru.org/ camp-koru		OPEN for applications	Unlimited	Out of state	N/A	Family Responisble	Camp Koru is a free outdoor adventure camp that helps young adult cancer survivors find healing and renewal beyond cancer. Participants, alongside other survivors, receive the tools, instruction, and encouragement required to take on a new challenge. The week is spent learning a new sport, accessing deep vulnerability, exploring the outdoors, and more, all while connecting with fellow survivors. Camp Koru is a retreat run by survivors, for survivors. Our camp counselors are all previous campers who have returned to lead and share their knowledge, experience, and inspiration with other survivors. Through this shared experience with peers, survivors learn to overcome fears and face life's challenges, and ultimately find their own ass-kicking
Camp	Varies		Patient, families, caregivers, healthcare workers	N/A	18-45 yo		See website for multiple upcoming adventures	One week	Online Application	https://firstdescents.org/prog rams/week-long-programs/	Website	Open	Unlimited	Out of State	N/A	Transportation- Family Responisble	
Camp	Varies		Siblings and families only	N/A	Any	TBD	TBD	2-3 days	Online Application	https://wildgrief.org/	website	CLOSED	Unlimited	In-State	N/A	Family Responisble	We believe in the healing power of both nature and peer support. At Wild Grief, we combine the two. We provide guided hikes at all levels, hour-long, day-long, and multi-day all focused on supporting each other while on our grief journeys. Grief is what we feel after the death of someone close in our lives and then the grief journey begins – we have to go through it and it is disorienting and often deeply painful. That is why our motto is Go Outside. Go Together. Go Through it. Wherever you are on your grief journey, we hope you can join us on



Specialty/ Program	Location	Group Name	Patient/ Sibling/ Caregiver/ Parent	Eligibility	Age Range	Day/Time	Next Group Dates	# of Sessions	How do I get into the group?	Link to flyer	Contact Person	Status	# of Participant s Allowed in Group		# of Patients Currently Enrolled	Billing (free/billed to insurance)	Camp Description
	Vashon C Island, WA	Goodtimes :	siblings (only 2 siblings can attend), breaved siblings			Jun. 25 - Jul. 1st, 2023	-23rd, 2023		Application	Camp Goodtimes — The Goodtimes Project		applications until 4/15/2023	Unlimited		N/A	Family Responisble	camp that is specifically designed to provide opportunities for personal growth, connection among children impacted by cancer, and a whole lot of camp-tastic fun—all in a medically supervised environment. And while campers are enrolled, parents get a chance to just breathe.
Camp \	G	Goodtimes - !! Mini Camp !	siblings (only 2 siblings can attend), breaved	Patient on or off treatment		Wed., 6/28/2023	Wed., 7/10/2023			https://www.thegoodtimespr oject.org/mini-camp	Website	CLOSED until Feb/March	Unlimited	In-State	N/A	Transportation- Family Responisble	Camp Goodtimes offers campers the opportunity to attend a resident camp that is specifically designed to provide opportunities for personal growth, connection among children impacted by cancer, and a whole lot of camp-tastic fun—all in a medically supervised environment. And while campers are enrolled, parents get a chance to just breathe.
	WA S	Camp Goodtimes - Sibling Ski Camp		Patient on or off treatment		Feb. 10th - 12th, 2023	N/A		Online Application	Camp Goodtimes — The Goodtimes Project	Website	CLOSED	Unlimited	In-State	N/A	Transportation- Family Responisble	
Camp \	G K A	Camp Goodtimes - Kayak Adventure Camp	Patients	Patients off treatment	18-25 yo	Jul. 30th - Aug.4th	N/A	One week	Online Application	https://www.thegoodtimespr oject.org/mini-camp	Website	CLOSED	Unlimited	In-State	N/A	Transportation- Family Responisble	Camp Goodtimes offers campers the opportunity to attend a resident camp that is specifically designed to provide opportunities for personal growth, connection among children impacted by cancer, and a whole lot of camp-tastic fun—all in a medically supervised environment. And while campers are enrolled, parents get a chance to just breathe.
Camp \	V	Virtal & !	Patients, Sibligs (18 yo or younger)& Parents	On-Treatment	18-25 yo	TBD	TBD		Online Application	https://www.campagapenw.o rg/copy-of-volunteer-info	Website	CLOSED	Unlimited	In-State	N/A	Transportation- Family Responisble	Camp Agape NW provides an all-expense-paid weeklong overnight camp for the whole family of a child with cancer. Camp Agape NW gives children with cancer a chance to feel normal, siblings a chance to feel special, and parents a time to be together. Through Greek Orthodox Church.
Camp	Varies (Camp Korey	Patients	On-Treatment	7-17 yo	TBD	TBD	1	Online Application	https://www.campkorey.org/ attend-camp/summer-camp/	Website	CLOSED	Unlimited	In-State	N/A	Transportation- Family Responisble	Part of SeriousFun Childrens Network, for children and families with week long summer camps, year round Camp to You, family weekends, young adult retreats, and more.
	1	ream	Patients, siblings, caregivers		Multiple age ranges	See Website for upcoming dates	See Website for upcoming dates		Multiple in Fall, Spring & Summer	https://www.campdream.org /apply/	Website	OPEN	30-40	Out of state	N/A	Transportation- Family Responisble	
Camp	Varies (Camp Kesem	Children who a	s N/A	18-Jun	TBD	TBD	N/A	Online Application	https://www.kesem.org/;seat	Website	CLOSED	Varies	In-State	N/A	Transportation- Family Responisble	

Mental health services through SCH Division of Psychiatry and Behavioral Medicine

Outpatient Psychiatry Specialty Clinics

- Mood and Anxiety Program
- PEARL Clinic (ADHD and Disruptive Behaviors)
- Behavior and Attention Management (BAM)
- Tic/Tourette's
- Gender Clinic (through Adolescent Medicine)
- Substance Abuse

- Neuropsychological Consultation Service
- Early Childhood Clinic
- Psychosis Clinic
- CALMA Clinic (Spanish)
- Eating Disorders Recovery Program
- Autism Center
- Crisis Care Clinic



https://www.seattlechildrens.org/clinics/psychiatry-and-behavioral-medicine

Mental health services through SCH Division of Psychiatry and Behavioral Medicine

Outpatient Psychiatry Specialty Clinics

- Disruptive Behavior Crisis Care
- OCD Intensive Outpatient Program
- Adolescent Partial Hospitalization Program
- Medication evaluation



Finding Mental Health Care in WA: A Class on Where to Start

- 30-minute classes offered to families who are seeking mental and behavioral health services for children or youth under 18
- Zoom, free, register in advance
- English and Spanish
- Recordings available
- Part 1: Outpatient Services; Part 2: Higher Levels of Care
- https://www.seattlechildrens.org/health-safety/mental-health-resources/findingmental-health-class/



Washington's Mental Health Referral Service for Children and Teens



www.seattlechildrens.org/wa-mental-health



https://www.seattlechildrens.org/globalassets/documents/clinics/wamhrs/wa-mhrs-family-flyer-english.pdf

WA Mental Health Referral Service for Children and Teens

- Phone: 833-303-5437; M-F, 8am-5pm; free
- Children and teens up to age 17 years
- Teens aged 13+ can contact service on own
- Call or submit online form / schedule intake with a referral specialist
 - Families provide mental health needs, location, insurance
- ~ 2 weeks after intake, referral specialist calls with info on 1-2 providers or agencies that meet needs and have openings
- Follow up from referral specialist to problem-solve barriers to accessing care



Therapist Directories

- Psychology Today
 https://www.psychologytoday.com/us/therapists
- GoodTherapy
 https://www.goodtherapy.org/find-therapist.html
- Association for Behavioral and Cognitive Therapies (ABCT) https://www.abct.org
- American Psychology Association Psychologist Locator https://locator.apa.org/
- BIPOC Mental Health Providers/Resources
 https://namiseattle.org/bipoc-mental-health-resources/
- Inclusive Therapists
 https://www.inclusivetherapists.com/



Cancer Lifeline



Helping you live your best life with cancer through FREE educational presentations, experiential classes, financial assistance, and personalized emotional support.



https://cancerlifeline.org

Choosing a mental health provider

What should I consider when looking for a therapist?

- Logistics/basics
 - Do they take your insurance?
 - Are they taking new patients?
 - Do they do in-person and/or virtual visits?
 - Where is their office?
 - What time slots do they have available?
- Qualifications
 - Is the therapist licensed?
 - What treatments do they provide?
 - Do they use treatment approaches that have been shown to work for the presenting problem? ("evidence-based treatment") www.effectivechildtherapy.org



Choosing a mental health provider

What should I consider when looking for a therapist?

- Experience
 - Do they have specialized training in work with kids/teens?
 - Do they have experience working with youth with cancer/medical conditions (and how important is this)?
 - Are they familiar with youth dealing with similar challenges?
- Are they a "good fit"?
 - · Do you feel comfortable with them?
 - It can take a few visits to decide if this is someone you feel you can make progress with
 - Process can take some time be persistent!



https://www.seattlechildrens.org/globalassets/documents/for-patients-and-families/pfe/pe1739.pdf https://effectivechildtherapy.org/tips-tools/advice-for-selecting-a-psychologist/

Psychiatry (medication) support

- Primary care doctor can talk to a child psychiatrist through the Washington Partnership Access Line (PAL)
- Monday through Friday, 8am-5pm
- PAL program funded by Washington's Health Care Authority
- https://www.seattlechildrens.org/healthcare-professionals/access-services/partnership-access-line/wa-pal/



Cancer-specific resources





Cancer-specific resources



• St. Jude

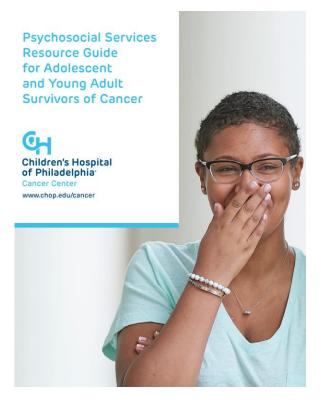
https://www.stjude.org/treatment/survivorship/participate-in-st-jude-life-study/tips-for-cancer-survivors.html

Children's Hospital of Philadelphia (CHOP)

http://www.chop.edu/centers-programs/oncology-psychosocial-services-program/health-resources#.V_QN7aKUJZ8









https://media.chop.edu/data/files/pdfs/oncology -aya-survivorship-manual.pdf

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Support for AYAs with Cancer

Virtual Support

The Cancer Patient

A satirical look at life as a cancer patient. @thecancerpatient on Instagram

Elephants and Tea

Virtual support network, magazine, webinars, and some in person events - all by AYAs for AYAs. elephantsandtea.com

Young Adult Survivors United

Groups, webinars, and financial assistance. yasurvivors.org

Cactus Cancer Society

Wide variety of virtual programs. cactuscancer.org

Stupid Cancer

Variety of social and educational activities. stupidcancer.org

Escape

LGBTQIA+ virtual meetups and events. escapeayac.org

Cancer Care

Groups & resources for patients & caregivers. cancercare.org/tagged/young adults



Camp Koru

projectkoru.org

Camp Mak-A-Dream

For ages 18-35 campdream.org

CancerCon

Annual conference by Stupid Cancer cancercon.org

Dear Jack Foundation

(specifically for couples) dearjackfoundation.org

Epic Experience

epicexperience.org

First Descents firstdescents.org

Send It Foundation

senditfoundation.org

True North Treks

truenorthtreks.org

Map of Other Camps

knowcancer.com/cancer-camps



Got Transition[®] is the national resource center on health care transition (HCT). Its aim is to improve transition from pediatric to adult health care through the use of evidence-driven strategies for health care professionals, youth, young adults, and their families.



Got Transition aims to help youth and young adults move from pediatric to adult health care.

Six Core Elements™
(For Clinicians)

Youth & Young Adults
(FAQs & Resources)

Parents & Caregivers (FAQs & Resources)

Resources & Research
(By Category)



https://www.gottransition.org/

General mental health resources

Patient and Family Education
 https://www.seattlechildrens.org/clinics/psychiatry-and-behavioral-medicine/patient-family-resources/

Seattle Children's Mental Health Resources
 <u>https://www.seattlechildrens.org/health-safety/keeping-kids-healthy/development/mental-health-resources/</u>

 ADHD, anxiety, autism spectrum disorders, depression, bipolar disorder, eating disorders, obsessive-compulsive disorder, oppositional defiant disorder



First Approach Skills Training (FAST) program

- https://www.seattlechildrens.org/healthcare-professionals/access-services/partnership-access-line/fast/parents-caregivers/
- Free, downloadable handouts, workbooks, and other resources
 - Anxiety problems
 - Depression problems
 - Traumatic events
 - Challenging behavior
 - Early childhood (ages 1-4)
 - Sleep tips
 - Teens' technology use
 - Racial discrimination and mental health



What is Anxiety?

Anxiety is a word for the uncomfortable feeling we all get when we think something bad might happen. It is a normal, natural feeling that everyone has.

Anxiety is often helpful, but sometimes it gets too strong and starts to interfere in our lives.

People use different words to describe anxiety, like *frightened*, *stressed*, *scared*, or *worried*. What words do you use?

	 	_





Did you know?

About one in every three teens has a big anxiety problem at some point...and one in three adults do too!

So, out of these 12 teens, about FOUR will have problems with anxiety at some point that keep them from doing things that matter to them.





Many famous people have struggled with anxiety! You probably even know a few, like Selena Gomez, Adele, Bill Heder, or Lady Gaga.

FAST – tips for caregivers

STRATEGIES

Validation: Use words to show you understand how they feel: "I get that this is hard for you"

Encourage with Confidence: Tell (and show) them you know they can do hard things: "I know it's hard <u>and</u> I know you can do this!" "I love you too much to keep helping you avoid"

Ask Questions after facing fears to help their success sink in: "What did you learn?" "How was that different from what you expected?"

Reward Brave Behavior: Use rewards to motivate and celebrate facing fears (it is hard!)

Model: Use your own actions to show your kids how to face fears even in the face of anxiety. Face fears with them!

Manage Your Own Distress: It's hard to watch your child being in distress. Remind yourself: "They can do this. Avoiding what they fear isn't helping them in the long run."

Tips for Facing Fears

Expect Anxiety! Your child should feel anxious when facing fears. That is part of learning.

Build Up: Start with a smaller, easier step if you're getting pushback or it's seeming too hard

Keep Practicing! It can sometimes take daily practice facing a fear for kids to begin to feel more confident.

Use Rewards to Motivate: Having a daily reward for daily practice is a good way to keep the ball rolling.





Infoaboutkids.org is an ongoing collaboration of the *Consortium for Science-Based Information on Children*, *Youth and Families*. Our goal is to promote healthy child and family development by highlighting science-based information for those who care for, or work with, children. Our site, updated annually, links to other well-established, trustworthy websites for parents, other caregivers, and professionals. Our monthly blogs will summarize science-based information on timely topics. Information provided on the site is meant to complement and not replace any advice or information from a health or education professional.





Resources for caregivers













- Cancer Lifeline
 - https://cancerlifeline.org/
- Cancer Pathways
 - https://cancerpathways.org/
- Courageous Parents Network
 https://courageousparentsnetwork.org
- Tips & self-help resources

https://keltymentalhealth.ca/parent-and-caregiver-wellbeing https://www.cci.health.wa.gov.au/Resources/Looking-After-Yourself





Momcology / Connections Program

https://momcology.org

- National nonprofit organization started by parents of children going through cancer treatment to offer support to other parents in partnership with a treating institution
- Connections Program
 - Program launched at Seattle Children's fall 2023 summer 2024 offering bimonthly support groups with any caregivers (not just moms), facilitated by SCH CBDC social workers.
 - Contact: Meghan Robbins, LICSW <u>meghan.robbins@seattlechildrens.org</u>





Caregiver support group

Caregiver Support Group

Dorothy O'Brien Center, Cancer Lifeline

Caregiver Cancer Support Group Facilitated by Marcia Robbins, MSW, LICSW 3rd Tuesday, 4-5:30pm

Dates for 2023:

January 17, February 21, March 21, April 18, May 16, June 20, July 18, Aug 15, Sept 19, Oct 17, Nov 21, Dec 19



Link to register: <u>Meeting Registration – Zoom</u>

Support for siblings

- WA Mental Health Referral Service
- Cancer Lifeline
- Art therapy groups at Seattle Children's
 - Art and Heart Space virtual art therapy group for cancer patients and siblings ages 8-13
 - Ink About It virtual art therapy group for siblings only ages 8-13
 - Sign up: https://forms.office.com/r/EHP9BRnk1V
- Camps!



Questions & Discussion

Questions?

Reflections?

Please complete brief survey to provide feedback and suggestions.

Thank you!





Hope. Care. Cure.