

Addressing Caregiver Mental Health in Pediatric Oncology

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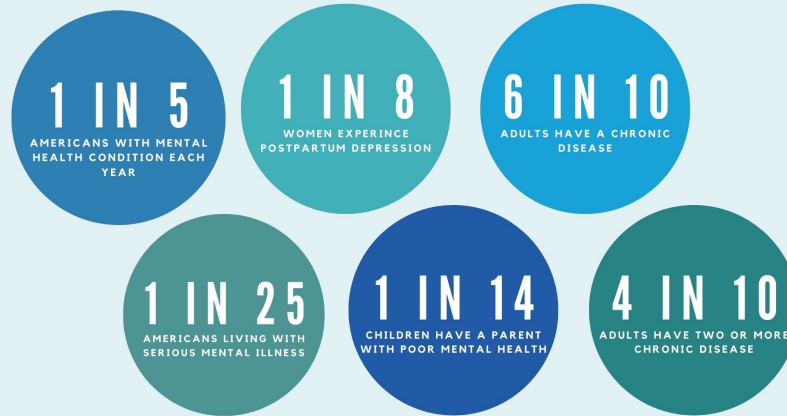
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I have no disclosures

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What is the Baseline?



Key substance use and mental health indicators in the United States: Results from the 2015 National Survey on Drug Use and Health. (2016); National Center for Chronic Disease Prevention and Health Promotion; Wolicki et al. (2021); Bauman et al. (2018)

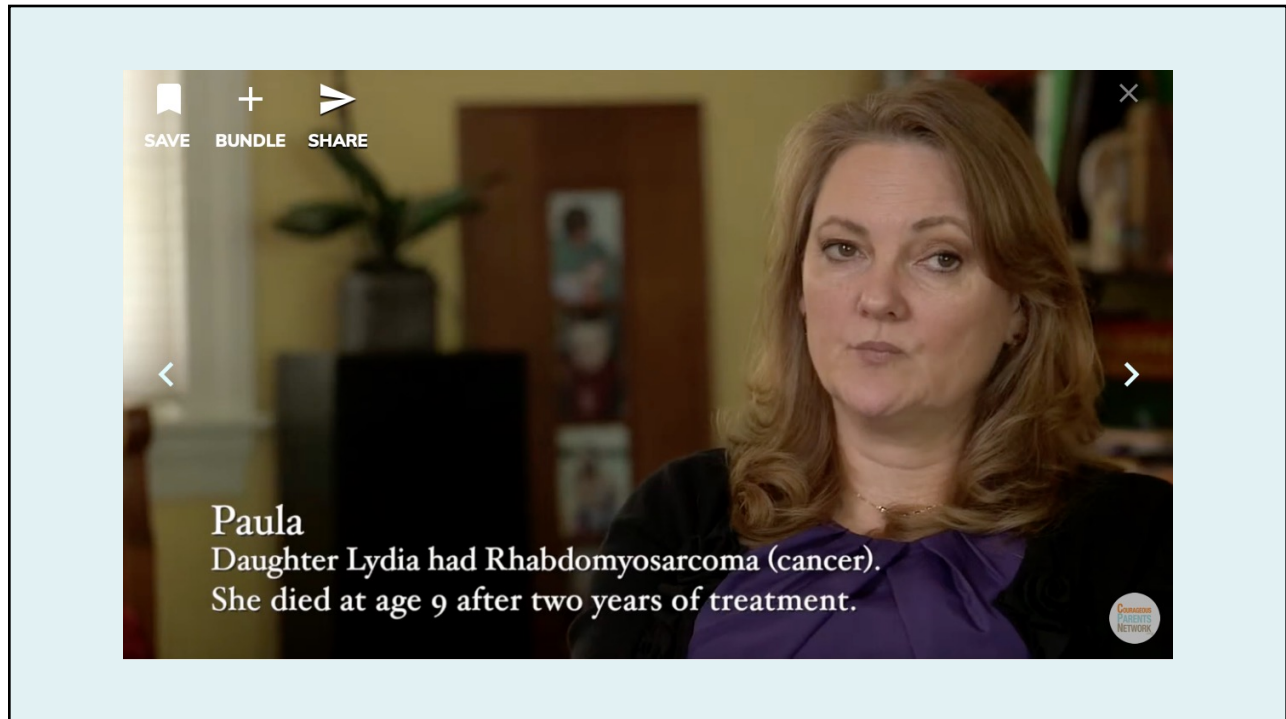
*slide courtesy of Dr. Dana Bakula

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Psychosocial Landscape for Parent Caregivers

- Existential distress
- Anticipatory grief
- Uncertainty
- Burden of decision making
- Communication with providers
- Advocacy/Being a Good parent
- Developing trust
- Fear of regret
- Financial concerns
- Marriage/partner
- Lone parenting
- Social support/lack of
- Managing logistics
- Caring for other children
- ACES
- Trauma
- SES

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Caregiver Mental Health

- Typically, highest levels of distress are at the time of diagnosis
- Distress also increases around transitions or decision points
- Report rates of mental health concerns vary
- Rates are higher than parents of health children



van Warmerdam, Zabih, Kurdyak, Sutradhar, Nathan, & Gupta (2019)

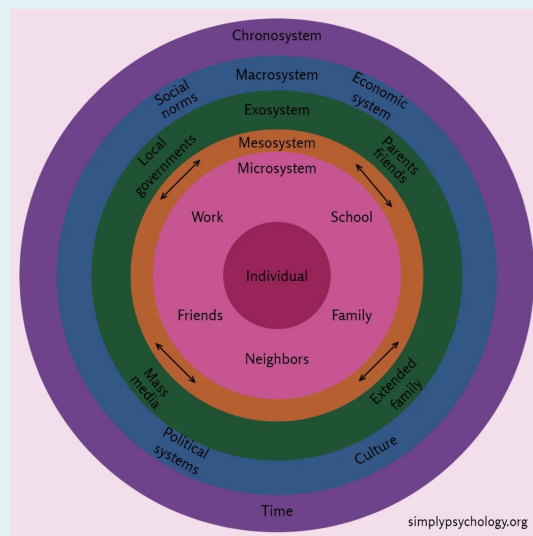
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Caregiver Mental Health

- Caregivers are **resilient** AND **find meaning** AND report **growth**
- But the impact of childhood cancer lasts long past treatment ends
- Sisk, Weng, & Mack, 2019
 - Five-year follow-up
 - “66% of parents had low piece of mind regardless of relapse status or prognosis”

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Bronfenbrenner’s Ecological Systems Theory



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Conclusions: Highly anxious parents are at risk for PTSS and may benefit from approaches that decrease anxiety during treatment and afterward. Enhancing self-efficacy related to follow-up care and identifying positive aspects of the traumatic experiences are suggested as treatment approaches for families after cancer treatment.

was comparable to that for hospitalized persons with anxiety disorders. The level of symptoms of PTS was higher than reported for parents of childhood cancer survivors. The relationship between anxiety and symptoms of PTS was significant ($r = .56, p < .02$). Pediatric oncology nurses should offer parents interventions to relieve high levels of anxiety and symptoms of PTS; some parents could also benefit from interventions that target uncertainty. © 2002, Sage Publications.

strategies (i.e., control, nurturance, and responsiveness) remained stable. **Conclusions:** Although maternal affective distress decreased following the initial diagnosis of cancer, sources of stress (e.g., caregiver burden) may remain stable, indicating the need for interventions to bolster parental coping resources.

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toms. Constructive problem-solving scores did not mediate these relationships. **Conclusions** The current findings suggest that illness uncertainty and dysfunctional problem-solving strategies, but not constructive problem-solving strategies, may play a key role in the adjustment of caregivers of children newly diagnosed with cancer. Interventions aimed at managing illness uncertainty and mitigating the impact of dysfunctional problem-solving strategies may promote psychological adjustment.

informing both screening and intervention practices. As Sharp et al. (2020) have also recently suggested, strengthening mental health support for caregivers early on in the child's treatment is needed. Prevention efforts delivered around the time of diagnosis

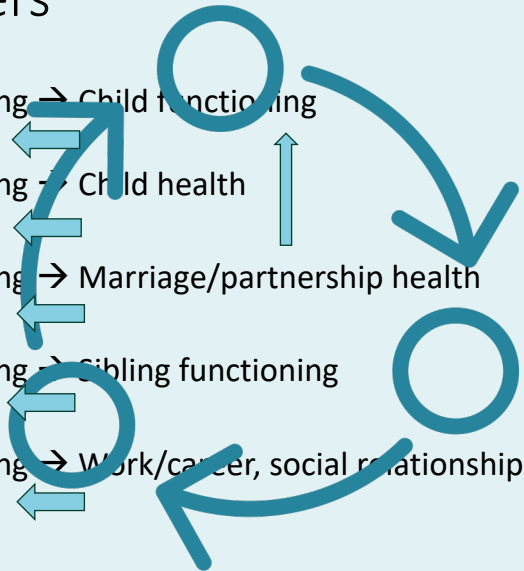
Implications: Parent distress is an important factor to evaluate in the context of pediatric cancer, as it appears to have implications for child quality of life, in addition to other child psychosocial adjustment outcomes.

only T1PAT and depression symptoms significantly predicted caregiver QOL at T2. Family psychosocial risk and caregiver depression symptoms near diagnosis predict caregiver QOL six months later. These results have important implications for supporting caregivers of children

parenting and family functioning challenges. Findings further highlight the importance of screening for even moderate parent distress and the possible impact of parent psychosocial interventions indirectly on parenting and family functioning. © The Author(s) 2023. Published by Oxford University Press on behalf of the Society of Pediatric Psychology. All rights reserved. For permissions, please e-mail: journals.permissions@oup.com.

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Why it matters

- Caregiver functioning → Child functioning
 - Caregiver functioning → Child health
 - Caregiver functioning → Marriage/partnership health
 - Caregiver functioning → Sibling functioning
 - Caregiver functioning → Work/career, social relationships...other things they have to do
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Why it matters



Caregivers deserve to feel
as well as they can.

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Standards of Care for Children with Cancer and their Families



Standards of Psychosocial Care for Parents of Children With Cancer (Kearney, Salley, & Muriel, 2015)

Parents and caregivers of children with cancer should have early and ongoing assessment of their mental health needs. Access to appropriate interventions for parents and caregivers should be facilitated to optimize parent, child, and family well being.

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What can be offered?

- Evidenced based screening measures
- Cognitive behavioral therapies
- Psychopharmacology

- Bright IDEAS! (Problem-solving skills training)
- Surviving Cancer Competently Intervention Program (SCCIP)
- Promoting Resilience in Stress Management for Parents (PRISM-P)
- Parent Social-Cognitive Processing Intervention Program (P-SCIP)



Salley, McDonnel, & Parris (in development)

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What supports are available to caregivers in pediatric oncology healthcare settings?

Standard:

- Social Workers
- Child Life Specialists
- Chaplaincy
- Family-centered rounds

Mostly standard:

- Pediatric psychologist

Harder to come by:

- Pediatric Psychiatrist
- Pediatric Palliative Care
- Peer-to-Peer Programs

Rare:

- Psychologist or Psychiatrist to treat parent mental health

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Then where do caregivers turn?

- Friends and family
- Patient/Disease organizations
- Nonprofit organizations
- Large expert groups with websites (COG, ACS)
- Social media
- Mental health treatment in the community?
- Or - nowhere?



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Getting Caregivers to Treatment – What are the Barriers?

Caregiver

- Deny concerns/refuse offers for mental health treatment
- Not enough time
- Overburdened
- Won't leave the child/bedside
- Prefer hospital providers vs. community
- Guilt or shame that they can't 'handle' it

Salley, Axelrad, Fischer, & Steuer, 2021

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Getting Caregivers to Treatment – What are the Barriers?

Community

- Community providers may not accept insurance
- Few openings/fully booked
- No knowledge/experience
- “Too sad”
- Cancellation policies, etc.

Salley, Axelrad, Fischer, & Steuer, 2021

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Getting Caregivers to Treatment– What are the Barriers?

Hospital

- Financial
- Team stretched thin
- Children’s hospitals “don’t treat adults”
- Providers are limited to documenting encounters in child’s chart
- Pediatric providers may feel “adult” skill set is limited
- No mechanism for billing parents’ insurance without a chart
- Concern for liability from administration/legal

Salley, Axelrad, Fischer, & Steuer, 2021

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But parents need help! Pathways to caregiver mental health care in pediatric hospital settings

Table 1. Pathways to address caregiver mental health in pediatric settings

Considerations	Treat and document as part of the child's care	Refer the caregiver to a provider outside of the hospital setting	Treat the caregiver within the pediatric hospital setting
Privacy/confidentiality	Risks privacy	Protects privacy	Protects privacy
Confusion/conflicting roles	Risks confusion on the part of the caregiver; risks to psychologist	Limits confusion and risks but could result in less integrated care if caregiver accesses referral	Limits these risks but increases the likelihood of cohesive, integrated treatment
Competence	May have competence	The referred provider would likely focus on adults	Prioritizes having competence in both pediatric and adult care
Access/barriers to care	Provides at least some support to a caregiver but with increased risks	Logistical barriers can interfere; caregivers may be reluctant to follow through	Reduces commonly reported logistical burden
Billing/financial burden	Billing “under patient’s chart”; potential risk to psychologist	Community providers may not accept insurance	Services can be billed to caregiver insurance if accepted by the hospital and approved
Documentation	Documenting “under patient’s chart” results in potential risk to psychologist and reduced privacy for caregiver	The document is separate and privacy is maintained; clinician may document caregiver referral patient’s chart	

Salley, Axelrad, Fischer, & Steuer, 2022

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Is it possible to treat caregiver mental health in pediatrics (or to facilitate treatment)?

- Yes
- Buy in from administration and providers
- \$\$ and other resources
- Examples: Memorial Sloan Kettering Cancer Center, Cincinnati Children's, University of Vermont Children's Hospital, St. Jude
- Flexibility

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How can you help?

- \$\$\$\$
- Educate families on the standard of care and empower them to advocate for services
- Advocacy (Big A, Little a)
- Reduce stigma around mental health services.



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How can you help?



Image courtesy of Dr. Dana Bakula

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How can you help?

All parents want to be a Good Parent.


Parents of children who have died of cancer report that their sense of having been a good parent at the end of their child's life helps them to emotionally survive their experience and their child's loss.

-Pamela Hinds (2009)

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How to find a therapist handout (English & Spanish)



How to Find a Therapist 
For parents and caregivers of children with medical conditions

Being the parent or caregiver of a child with a medical condition can be very stressful. Some medical experiences you have with your child may be traumatic. As many as 1 in 8 adults has a mental health concern like depression, anxiety, or post-traumatic stress disorder (1). The chance that you will experience a mental health concern increases when you have a child with a medical condition. It can be hard to find the time or resources to take care of your mental health, but taking care of yourself is important for both your wellbeing and your child's.

A therapist can help you manage stress, worry, sadness, anger, grief, and more. Therapists are licensed mental health professionals who can listen to your concerns and help you solve problems. Therapists can teach you strategies that help you manage difficult emotions, thoughts, and memories. Therapists can also help you to improve communication with your loved ones or work through problems in your relationships. The steps below can help you find a therapist.

As you follow these steps, remember that deciding to find a therapist is a big step! It can feel scary, and you may feel like you don't have time to put your needs first. But, it is worth it.

STEP 1: FIND OPTIONS

There are multiple types of therapists, including psychologists, licensed clinical social workers, licensed professional counselors, and psychiatrists (though psychiatrists most often focus on medication management). They each have slightly different training, but all have a common goal of working with you to support your mental health. To find a good therapist, start by finding out your options. Here are some ways you can start:

1. **Search online.** You can use websites such as EFTreatment.SAMHSA.gov, Locator.APA.org, or PsychologyToday.com to find therapists in your area.
2. **Ask around.** Ask friends and family if they have recommendations. Ask other parents and caregivers you know who have dealt with similar experiences, as well as members of your child's care team such as a social worker or psychologist. You should also ask your primary care doctor or other trusted professionals that may have a recommendation.
3. **Call your insurance company or go to their website.** Your insurance company can tell you what mental health services are covered by your insurance plan, and which specific therapists are covered. Call the phone number on the back of your insurance card or visit the website on your card to learn who is covered by your insurance. Your employer may also have an Employee Assistance Program that provides mental health care.
4. **Call your local health department or go to their website.** In most areas, there are low-cost, community mental health services. Ask your local health department for more information.

This handout was created by Dana Bourne, PhD, with input from the Caregiver Wellbeing Outreach Subcommittee and employees who generously donated their time to provide feedback. (1) The relationship use and mental health indicators in the United States Results from the 2018 National Survey on Drug Use and Health. Bethesda, MD: Center for Behavioral Health Statistics and Quality, Substance Abuse and Mental Health Services Administration; 2019.

How to Find a Therapist Continued 

STEP 2: ASK QUESTIONS

Not all therapists have the same training or experience. Ask questions before deciding to work with a specific therapist. You can ask to have a phone consultation before scheduling a visit or ask before during your first appointment to help decide if this is the right therapist for you. You may want to ask a few therapists before you find the right fit, and that is okay!

Ask about their expertise. Ask about their qualifications and experience. Do they use strategies (based on research) that are called "evidence-based" strategies?
Are you a licensed therapist and how long have you been licensed?
What experiences do you have with my specific concern?
Are you familiar with caregivers of children with medical conditions?
What treatments do you have? Have they been proven to help with feelings like depression, anxiety, anger, or grief?
Ask about their policies. How well do their policies meet your needs as a parent/caregiver?
What are your fees, and do you take my insurance? If you don't take my insurance, do you have a sliding scale fee system to help lower the cost?
What are your cancellation policies? Are they flexible if I need to cancel because my child is hospitalized or has a medical appointment?
Are you willing to speak to someone on my child's medical team or open line learning about my child's condition and what it takes to manage it?
Do you offer telehealth visits? Do you have evening or weekend hours?

STEP 3: MAKE AN APPOINTMENT

Once you find one or more good options, choose a therapist and make an appointment! If one of the therapists you found has openings, consider joining the waitlist for multiple therapists.

WHILE YOU WAIT FOR YOUR APPOINTMENT...

Talk to your loved ones about how you are feeling and find small ways to get support, such as phone call with a friend, support with children, and evening or getting regular sleep and food. You can also dial "988" to be connected with the Suicide and Crisis Lifeline, or text with a friend through the Crisis Text Line by texting "988" to 734-746.

ASK MORE! The Caregiver Wellbeing Special Interest Group is a group of mental health professionals dedicated to the promotion of wellbeing for caregivers. Interested in joining? Check out our webpage. Follow us on social media for updates and evidence-based caregiver wellbeing tips. www.caregiverwellbeing.org @CaregiverWellbeingSP @CaregiverWellbeingSP

Handout was created by Dana Bourne, PhD, with input from the Caregiver Wellbeing Outreach Subcommittee and employees who generously donated their time to provide feedback.

<https://div54cwsig.wixsite.com/caregiverwellbeing/resources>

Questions?

How are you?