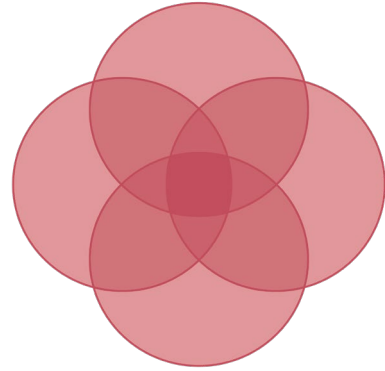


WELCOME!

**PARENTING THROUGH A HEAD AND NECK CANCER
DIAGNOSIS, TREATMENT AND INTO SURVIVORSHIP**





HEAD AND NECK CANCER
ALLIANCE
HEADANDNECK.ORG

PARENTING THROUGH A HEAD AND NECK CANCER DIAGNOSIS, TREATMENT AND INTO SURVIVORSHIP

Moderator:

Beverly Garber, NP, CORLN

Family Systems and Coping Specialist:

Emily McDaniel, MA, CCLS

Survivors:

Jessica Dagley, Willie Pelote, Sr, Michael Murphy, MD

MICHAEL MURPHY — FUN FATHER OF TWO KIDS



DAUGHTER'S DIARY

7/2/20

Daddy leaves and comes back early most mornings now. He mostly eats brie on bread now. He is also much, much, much more tired. Sometimes he has a smoothie or a protein bar. Hugh and I go biking a lot, but Daddy doesn't bike any more. Daddy is eating breakfast behind me as I speak. He just discovered that he cannot taste the cinnamon on his cereal. He even tried pouring some into his spoon. Nothing. I wonder what it feels like to not taste anything.

6/25/20

Today, Daddy seems MUCH better than he did yesterday. 👍 Mama says that it's because Daddy got chemo the day before yesterday so yesterday the chemo that is his medicine made him sick. Such a powerful poison medicine! He lay in bed almost all yesterday afternoon. He came out after dinner and was HICCUPPING like crazy! Mama says it is one of the side effects of the chemo. Daddy has been eating lots of snacks.

6/24/20

Daddy left for radiation this morning. When we picked him up from chemo yesterday, his voice was hoarse and he seemed worried. He had a blue bandage around his wrist from where the chemo had been injected. Oh, and I can add to the list of new things.

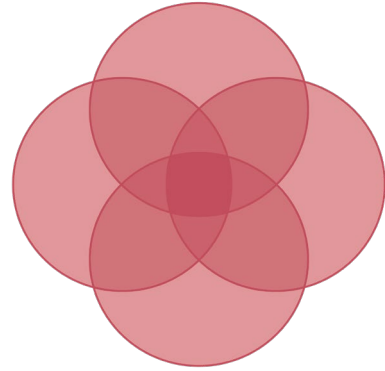
- A bunch of pillows
- A gargling pitcher
- A food tray
- A cancer food sheet
- A smoothie maker

Mama says that we will make a smoothie today. I think that it will make smoothies smoother so that they go down the throat easier. It is called a NUTRIBULLET. Such a cheerful name.

7/23/20

Not much is new since I last wrote. Daddy infuses every day, almost every meal. (By infusing I mean taking food into the tube in his stomach. It is weird to see him come to a meal with his shirt rolled up, a syringe, and a protein shake.





HEAD AND NECK CANCER
ALLIANCE
HEADANDNECK.ORG

CHILD LIFE PERSPECTIVE: PARENTING THROUGH ILLNESS AND INTO SURVIVORSHIP

Emily McDaniel, MA, CCLS

Certified Child Life Specialist | Children of Adult Patients

UC Davis Comprehensive Cancer Center, Sacramento, CA

ejmcdaniel@ucdavis.edu

WHAT IS A CHILD LIFE SPECIALIST?

Scope: Adult patients who are experiencing a life altering illness, injury, or who are nearing end of life with minor children.

Main goal: Collaborate with families to **maximize family coping** through communication and connection.

Theories that ground this work:



Family Systems



Child
Development



Stress and
Coping



**Cancer patients that have
children under 18 years old.**

25%

Family Communication

**Open communication
confirms that families will
weather the storm together.
This is empowering.**



HOW MUCH CAN A CHILD CARRY?

- Keep information clear and simple.
- Dose information.
- Separate children if age/temperaments are greatly different.
- Use tools to enrich understanding.
- Model coping ideas.



"I HAVE SOME IMPORTANT INFORMATION I'D LIKE US TO TALK ABOUT..."

- 1 **Simple background:** "You know how I've had some trouble swallowing...well, I went to the doctor the other day."
- 2 **Recent happenings:** "They did some testing and took pictures of my neck. They found out that the lump in my neck is a group of unhealthy cancer cells."
- 3 **Assess:** Check for understanding and to see if they have other information about cancer.
- 4 **Brief explanation:** "There are different types of cancer. The type I have is cancer in my neck. For me, this means there are unhealthy cells collecting in one place. This is causing pain in my neck."
- 5 **What's coming up:** "The doctors and team are going to create a treatment plan. This plan is going to help get rid of the cancer. I will start by having surgery."
- 6 **Transition:** Address questions, feelings, and switch gears.



Analogies can be helpful...

1

Healthy cells are players on “Team Healthy” and each have a job to do. Cancer cells don’t have a job in the body and get in the way of the healthy cells keeping the body working well.



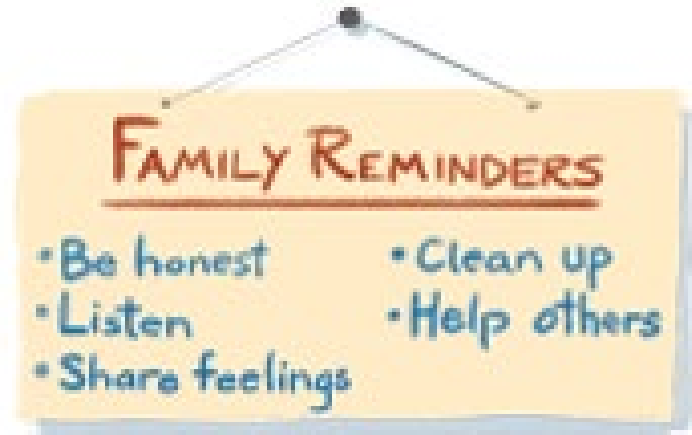
2

You can think of cancer like weeds in a garden. Weeds get in the way of a healthy garden but there are ways to help get rid of the weeds...



SUPPORT IN MOTION

- Regular family meetings and planning sessions
- Family coping ideas
- Maintaining routines and boundaries
- Readily available information | "Coffee Table Books"
- Expressive activities
- Support groups and other outside resources



CHILDHOOD COPING

Coping Considerations:

- Development
- Baseline temperament
- Expressive patterns



Seeking additional help:

- Is the child engaging in regular activities?
- Are earlier coping strategies no longer helping?
- Is the child trying to create a sense of control in other ways (acting out, repetitive behaviors, etc.)?



If behavior isn't getting to a new normal that is manageable, persists for more than a few weeks and/or is getting worse, **connecting with a mental health professional is best.**

RESOURCES

- **Wonders & Worries**
 - Resources [app, topic specific, etc.]
 - Parent webinars
 - Helpline
- **Pickles Group**
 - Family support kit
 - Parent webinars
 - Virtual support groups for children
- **Bright Spot Network**
 - Resources
 - Groups and parent webinars
 - Free books!
- **UC Davis Cancer Center**
 - Resources
 - Support groups
 - Teen Advisory Council
- **Camp Kesem**
 - Free camp programming for children impacted by a parent's cancer
- **Parenting At a Challenging Time (PACT)**
 - Website/resources
 - Toolkit for teachers



**Scan QR Code for
Resource List Links**

IMPLICATIONS | GRATITUDE

- **Clinicians:** "We realize this situation impacts the whole family. There are resources geared for children coping with a parent's illness."
- **Parents:** "Parenting through this illness is challenging. Are there resources to support families in my situation with minor aged children?"



REFERENCES

1. Association of Child Life Professionals (ACLP). (2018). ACLP Position Statement on Child Life Practice for Children of Adult Patients. Retrieved from https://www.childlife.org/docs/default-source/about-aclp/cbp-on-cl-practice-for-children-of-adult-patients.pdf?sfvrsn=595bb04d_4
2. Fryar, K. (2022). *Difficult Conversations with Children*. Austin: Wonders & Worries.
3. Marshall S, Fearnley R, Bristowe K, Harding R. The perspectives of children and young people affected by parental life-limiting illness: An integrative review and thematic synthesis. *Palliat Med*. 2021 Feb;35(2):246-260. Epub 2020 Nov 19.
4. Phillips F, Prezio EA. Wonders & Worries: evaluation of a child centered psychosocial intervention for families who have a parent/primary caregiver with cancer. *Psychooncology*. 2017 Jul;26(7):1006-1012.. Epub 2016 Mar 8.
5. Rauch, P., & Moore, C. (2010). *A Population-Based Estimate of Cancer Survivors Residing With Minor Children. Cancer*.
6. Rauch, P. K., Muriel, A. C., & Cassem, N. H. (2002). Parents With Cancer: Who's Looking After the Children? *Journal of Clinical Oncology*, 4399-4402.
7. Semple, C. J., & McCance, T. (2010). Experience of parents with head and neck cancer who are caring for young children. *Journal of Advanced Nursing*, 1280-1290.
8. Sutter C, Reid T. How do we talk to the children? Child life consultation to support the children of seriously ill adult inpatients. *J Palliat Med*. 2012 Dec;15(12):1362-8. doi: 10.1089/jpm.2012.0019. Epub 2012 Sep 14. PMID: 22978620.
9. Tucker, Anita R.; Sugerman, Deb; Zelov, Ryan. On Belay: Providing Connection, Support, and Empowerment to Children Who Have a Parent With Cancer. *Journal of Experiential Education* 2013 36:2, 93-105

JESSICA DAGLEY — PROUD MOTHER OF THREE CHILDREN



WILLIE PELOTE — DAD TO TWINS





Our vision is that every child impacted by a parent's cancer is never alone.

Join us at kesem.org. **Programs open Jan 23!**

Kesem provides free, year-round, mental health support to children ages 6-18 and their families.

Camp Kesem, Kesem's flagship program, is a free, week-long overnight summer camp experience.

We focus on creating fun experiences that help children escape - even if for a short time - the challenges of coping with a parent's cancer diagnosis. More than 100 Kesem chapters offer Camp Kesem.

The following programs are NEW in 2024:

Club Kesem is an age-based, national virtual meet-up offered monthly for more connection opportunities from coast to coast.

Kesem Gatherings are in-person, hours-long programs offered locally monthly for more frequent time together annually. Seven Kesem chapters currently offer Gatherings.

Kesem Better Days are in-person, full-day programs offered locally multiple times a year for more extended time together annually. Six Kesem chapters currently offer Better Days.

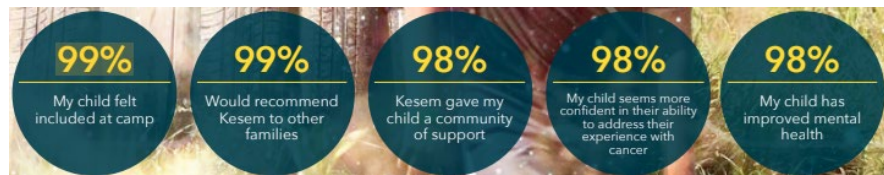
Kids and their families also receive grief support, care packages, birthday and holiday cards, and community events.

"Camp Kesem helped my daughter's confidence so much, and this has carried on after the end of camp. I cannot say enough about how great of an impact this program has had on my child's emotional well-being."

-Kesem Parent, 2023



Family resources are available through the website above!



CAMP KESEM SEND OFF!



Beverly and her husband with
8yr old daughter, "Lemur"

Ready for Camp Kesem 2023!

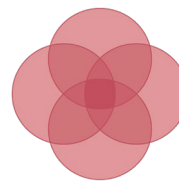


RESOURCE SLIDES

HNCA Resources

- Head and Neck Cancer Alliance, www.headandneck.org
- Online Community Support Group on Inspire ,
<https://www.headandneck.org/support-community/>
- Peer-to-Peer Program, Sign Up for a Mentor,
<https://www.headandneck.org/peer-to-peer-program/>





HEAD AND NECK CANCER
ALLIANCE
HEADANDNECK.ORG

QUESTIONS?

Thank you for attending

Contact us:
Head and Neck Cancer Alliance
info@headandneckcancer.org

