

How to Support Children through a Parent or Loved One's Cancer

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Bright Spot Network

Helping families through cancer.



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**GILDA'S CLUB
MADISON**
An Affiliate of the
CANCER SUPPORT COMMUNITY

Increased number of families are facing cancer

Cancer incidence is rising among adults of childbearing age:

- Rates of cancer among adults ages 30–39 has increased by 19% between 2010–2019

(Koh, B. et al., 2023)

Which means more children are navigating a parent or guardian's cancer

- Almost **3 million** kids and teens have a parent with cancer, or who had cancer
- **1 in 5** newly diagnosed cancer patients have children 18 or younger

(American Academy of Children & Adolescent Psychiatry, 2019)

Cancer affects the Whole Family



“...children’s health and functioning are closely tied with those of their parents, [and] the young offspring of these survivors are at increased risk for problems in emotional, social, cognitive, behavioural, and physical functioning domains.”

(Weaver, K.E. et al., 2011)

What We Do

With rates of cancer on the rise among adults ages 20 – 49, Bright Spot Network fills a crucial resource gap, as the only national non-profit solely focused on supporting parents of young children as they navigate the unimaginable task of parenting with cancer. Our services to families are organized within the following categories.



Support and Care

Provide resources for parents with young kids who are navigating their own cancer diagnosis and treatment.



Community Building

Bring together parents and families to support their well-being and establish healing connections.



Public Leadership

Build awareness about the emotional and economic needs of families in which a parent has cancer.

Community

Parents with cancer who were diagnosed during pregnancy or with young children, living anywhere in the United States, as well as partners.

Mission

Bright Spot Network provides young cancer survivors who are parents of small children with a safe space for individual and familial healing, recovery, and reconnection.

Our Programs

Connecting Parents

- Virtual Support & Meet-up Groups
 - Parents in Active Treatment & Early Survivorship
 - Parents with Stage 4 Cancer
 - Partners
 - Bereaved Partners
 - Parents of Color
 - Parents in Long Term Survivorship
 - Couples
- Closed Facebook Groups



Our Programs

Connecting Kids & Families

- Bright Circle & Club
- Teddy Bear Clinics
- Exchanges
- Bright Birthday Cards
- Family Workshops



Our Programs

Tools to Talk to Kids

- Bright Reads
- Discussion Guides
- Customizable Coloring Book
- Coloring Pages
- Feeling Wheels



Talking about cancer with your kids is hard. We get it. Bright Reads books are one way to start this difficult conversation.

This guide is intended to be used by parents and guardians, grandparents and loved ones, or any loving member of your community. You'll notice the questions are posed from the perspective of a parent with cancer—please change the language to fit your needs.

We've listed suggested ages for the discussion questions and activity ideas, but you know your child the best. These questions may not work for every child depending on language development, understanding of a parent's cancer, and all of the things that make our kids unique.

Here are some helpful questions and sentence starters to use with your child when you are reading together, when a moment of connection opens up, or anytime you need them:

- What did you think of this story? How did it make you feel?
- What is similar or different between this story and our family's story?
- What did you learn from this story?



It is helpful to keep sentences short and to the point when talking young children about your cancer diagnosis. Here are some sentences to consider and edit to your specific situation:

- I have cancer.
- You can't catch it. (Don't worry, you get it from you or another part.)
- I am getting a medicine called chemotherapy / radiation.
- You can hug and squeeze me all you want and you will never catch it from me.
- You can always ask the questions about cancer and how I feel.
- Cancer is a sickness, illness or disease depending on your family's understanding.
- I am going to the doctor to get better.
- The medicine they need to help me get better.
- Nothing you do or say will hurt me or cause me to get cancer.

Please keep in mind that some children will not want to talk about their feelings. Some children will have a million questions. Other children might have huge emotions and big behaviors. It's all OK. Let your children know that you love them no matter what and that they can come to you when they are ready (and over-and-over-again).

Adapted from you to the following professionals who contributed to us to meet your goals: *Tara Hodges, LCSW, CHC, C | Sarah E. Powers, PhD | Lauren Hagan, MS, MPH, LCSW, C | Sarah Ryan, MA, CD

Our Programs

Education & Empowerment Resources

- Webinars
- Downloadable Guides
- Family Navigation Meetings
- Blog
- Bright Grant
- Bright Box
- Postpartum Box



Parenting with Cancer: What Kids Understand and How You Can Help Them

What does my child understand about cancer?

Our job as parents is to help our children process the world around them, understand their emotions and express what they're feeling in developmentally appropriate ways. All of our kids' behaviors are communication and our job is to be detectives—which can be really difficult!

Infants and toddlers may not understand much of what's happening, but even babies can sense changes in their environment. So, if there's a change in the family system, even little ones can feel it.

Preschoolers are all about themselves! Their main lens is "how does this affect me right now?"

They may:

- A limited scope of understanding
- An emphasis is on the here and now
- A focus is on how it affects them

Elementary school children are starting to broaden their thinking a little bit.

They may:

- Be wondering: Did something I do cause this? Did I wish something bad?
- Show an interest in the biological aspects of cancer: where in the body are things happening?
- Ask broader questions about what's happening, including concerns about death

Middle school children are starting to understand more complexities.

They may:

- Have heard about cancer before
- Think more abstractly or question their belief system
- Have broader concerns (worries about the death of a parent or that they may get cancer)
- Be inclined to seek support from peers rather than from adults

Teens understand complexities.

They may:

- Have concerns related to their own self-identity; they don't want to feel different from peers
- Be caught between breaking away but also needing support
- Be inclined to seek support from peers rather than adults
- Need to hide their feelings to maintain a sense of control

Remember: You know your child the best. Each child's own developmental path will have a great impact on how they process, experience and understand a cancer diagnosis.

Resilience



- Ability to “Bounce Back” (“Spring Back”)
- Hardiness
- Elasticity, Flexibility
- “Bend without breaking”
- Capacity to endure, adapt
- “Ordinary Magic” (it’s more common than we think)

(Ann Masten, 2014)

Resilient Characteristics

- **Belonging**
Close attachment relationships, community bonds, empathy, authenticity, agreeableness
- **Control**
Internal locus orientation, regulation, balance
- **Problem Solving**
Flexibility, creativity, motivation to overcome challenges
- **Confidence**
Positive self-view, mastery of skill, responsibility
- **Insight**
Perspective, reframing
- **Perseverance**
Realistic optimism, hope, meaning-making, belief in something bigger

Resilient Characteristics

- **HUMOR...**

...combines "optimism with a realistic look at the tragic."
(Ann Graber)



Resilience



- Combination of inner and outer strengths
- Vulnerability: The birthplace of resilience
- Resilience is a muscle we can help kids build

“The greatest gift you can give your children is not protection from change, loss, pain, or stress, but the confidence and tools to cope and grow with all that life has to offer them.”

Wendy Schlessel Harpham, MD, “When a Parent Has Cancer:
A Guide to Caring for Your Children” (2004)

“Children are resilient. The life force burns brightly in them; with our help, they can bounce back even from shocks that might devastate an adult.”

Kathleen McCue, M.A., C.C.L.S., “How to Help Children Through a Parent’s Serious Illness” (2011)

What children need when a loved one has cancer

1. **Safe, reliable and empathetic caregivers**
2. **Predictable routines and preparation for changes**
3. **Open, honest and developmentally appropriate communication**

What children need when a loved one has cancer

- Parents have a unique expertise on their children
- You may not have all of the answers to their questions, but your presence, attention, and willingness to talk is most important.
- Honesty really is the best policy

Safe, reliable and empathetic caregivers

- Immediate concerns
 - Four S's: Safe, Seen, Soothed, Secured (Siegel & Bryson, 2012)
 - Physical care for children and plan for continuation of meeting basic needs
 - Small, intimate, consistent group of caregivers (minimize disruption)
 - Attachment (especially for infants/toddlers)
- Long-term planning
 - Disability plan, Advance Directives, Guardianship, Wills/Trusts

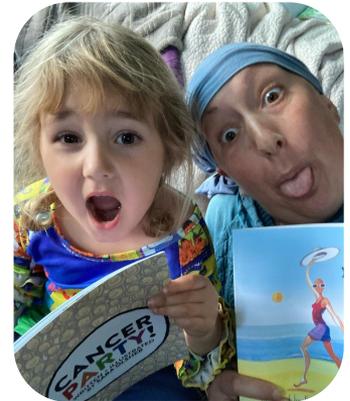
Safe, reliable and empathetic caregivers

- Support team:
 - Inner Circle
 - Collateral supports
 - Peer connections (for kids and adults)



Safe, reliable and empathetic caregivers

- Points of connection, everyday
- Physical touch and proximity
- Maintaining expectations and rules
- Making room for flexibility and looking beneath the behavior
- Helping kids to process big feelings
 - Play, play play
 - Art & creativity
 - Movement
 - Mindfulness
 - Books



Predictable routines and preparation for change

- Consistency in the midst of confusion provides reliability, stability and a sense of normalcy
- Consider the use of visual schedules
- Give your child a heads-up when you know change is coming



mighty-bright

Open, honest and developmentally appropriate communication

- Use short, simple phrases
 - *expand as their ability allows*
- Include words your child will overhear
 - *ex. cancer, chemo, radiation*
- Utilize children's books about cancer and emotions
- Avoid metaphors with young children
 - *they are concrete thinkers*
- Consider planning out your message and practicing beforehand
- Be careful of promises

Open, honest and developmentally appropriate communication

Mommy has cancer.

She is going to the doctor to get better.

She is getting a medicine called chemotherapy/radiation.

The medicine may make mommy feel sick and tired.

You can hug and snuggle mommy all you want and you will never catch cancer.

Nothing you did or said caused mommy to get cancer.

You can always ask us questions about cancer or how mommy feels.

Open, honest and developmentally appropriate communication

- **4 C's of Cancer:**
 - Can I **CATCH** it?
 - Did I **CAUSE** it?
 - Can I **CURE** it?
 - Who will take **CARE** of me?

([Canadian Virtual Hospice](#))

Open, honest and developmentally appropriate communication

- **Cancer is not your fault.**
 - No action, words, or thoughts made someone get cancer.
- **Cancer is not contagious.**
 - Try to avoid using the word “sick” in describing cancer, since it makes kids think of the cold, flu or COVID.
- **It is not your job to make me feel better.**
 - Your snuggles, hugs and kisses are all I need from you.
- **No matter what happens, you will be loved and cared for.**
 - This will require a bigger discussion for older children.
- **You can ask me any questions, now or later.**
 - And I will let you know when I have new information or if anything changes.

Open, honest and developmentally appropriate communication

- Unique kids, special approaches
- Showing emotions
- Consider timing
- Listen for the underlying messages
- Expect the unexpected
- How to handle school
- Divorced or separated parents
- Talking about death and dying
- Managing Your message
- Wash. Rinse. Repeat.

“Life is not fair. Life hurts. Life is good. These three seemingly incompatible expressions are really three parts of the whole of living. They are threads woven through the tapestry each one of us creates as the visible expression of our being a part of humanity. To accept these three is not to abandon hope or optimism, or to deny our real grief. To accept them is to rid ourselves of the unnecessary suffering that comes from struggling against these three truths and trying to make them something they are not.”

(Coloroso, 2000)

Signs of Distress

“Is my child functioning in their life?”

- Disturbances in the big four:
 - Development
 - School
 - Sleep
 - Eating
- Persistent change in mood or patterns of behavior
 - Exploding/Withdrawing
- Dysfunctional role shifts
 - Parentification, surrogate partner, caregiver

Professional Support

Individual and Family Therapy

Look for therapist who is trained in family systems, children and chronic illness

- Play Therapy
- Art Therapy
- Eye Movement and Desensitization and Reprocessing (EMDR)

Community Support

School

- Social Worker, Counselor, Nurse, Teacher, Coach

Hospital

- Social Worker, Child Life Specialist

Spiritual Center

Camps

- Kesem

Other Families Facing Cancer

Local in-person support groups

- Cancer Support Community

Online Support

- Bright Spot Network, Wonders and Worries, Pickles

What real families have to say about navigating cancer

Cancer has taught me and my family:

- How to be empathetic
- How to be self-reliant and confident
- How to connect with and appreciate each other
- How to appreciate life and find the silver linings

(Hodgson, Parental Survey of Resilience, 2008)



PEOPLE WILL FORGET
WHAT YOU SAID,
PEOPLE WILL FORGET
WHAT YOU DID,
BUT PEOPLE WILL NEVER FORGET
**HOW YOU MADE
THEM FEEL.**

- MAYA ANGELOU -



THANK YOU!

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