

COPING with **CHILDHOOD** **CANCER**

While nobody's journey is the same, it is important to advocate for mental health resources and support along the way



United Therapeutics
ONCOLOGY

COPING and ADVOCATING

Step-by-Step

When a child is diagnosed with cancer, it can have an overwhelming effect on the entire family. Feelings of fear, anger, confusion, and sadness are common and expected throughout the journey. The initial focus is often on treating the cancer and its physical symptoms, but it is just as important to address the emotional impact of cancer as well. Knowing when and how to do this may be difficult for families. The Mattie Miracle Cancer Foundation saw this need and worked with a team of experts to create the **Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC)**, a set of evidence-based standards that were built to help your healthcare team better identify ways to support positive coping throughout the cancer journey.

This guide uses concepts and ideas from these standards of care in order to help you and your family advocate for resources that may be available to you.

To learn more about the standards and read about Mattie's story, please visit mattiemiracle.com



It's not just about the medicine!™



DIAGNOSIS

Coping with your child's cancer diagnosis can be overwhelming. Consider the following suggestions to help set a good foundation for you and your child's mental health throughout the journey.



Establish a relationship between the healthcare team and family

The healthcare team is there to support you and your family. It may seem simple, but embracing your relationship with them as early as possible is important so that they can be a familiar and consistent source of support for you and your family.



Introducing family members by name (instead of “patient’s sister” or “patient’s grandmother”) to the healthcare team can help all family members feel included and considered. This can be especially helpful for siblings.



While all team members are there to help, the psychosocial care experts are there to help you and your child navigate the medical system as well as your feelings and emotions. Psychosocial care experts often include social workers, psychologists, psychiatrists, art therapists, physical and occupational therapists, chaplains, child life specialists, and palliative care clinicians. They also can help you to discuss difficult topics with your child and other family members, and advocate on your behalf to the medical team.

Set expectations

- » It’s normal for your child to feel scared or anxious before starting treatment or having a procedure done. However, many children can cope with difficult experiences if they know when it will happen and how long it will last. The healthcare team will help prepare your child ahead of time. You can share what might help your child to stay calm during the experience.
- » A social worker, nurse, child life specialist, or another member of the healthcare team can help you find the right words to explain medical treatments or procedures to your child.
- » Some children find “medical play” or “play therapy” helpful. This is where they can watch the procedure done on a teddy bear or doll.



Talk to a nurse or child life specialist if you are interested in setting this up for your child

Identify financial resources and support

Finances are often a stressor for many families. If this is your situation, you are not alone. Help is available:



Talking with a hospital social worker or financial counselor from the start can be helpful to identify organizations or resources that may be able to help with medical bills, cost of prescriptions, travel and parking expenses, food, housing, childcare for siblings, and more.

Remember that you can ask for financial assistance at any time during your journey. It is never too late to ask for help

Learn how to cope together

Many parents and caregivers of children with cancer experience high levels of stress and anxiety. Learning to cope as a team with your spouse or partner during this challenging time is an important part of supporting your mental health.

- » **Dyadic coping**, or coping as a team (also referred to as a dyad), is as simple as checking in on how the other person is feeling and how they are coping and managing emotionally with their child's cancer in an open and honest way.
- » Coping as a dyad can be challenging when partners have different coping styles. If this is the case, the recommendation is to respect each other's differences, and to listen without judgment.



Positive examples of dyadic coping include helping each other with daily tasks and sharing responsibility when possible, offering empathetic understanding, seeking information, and solving problems together.



Negative examples of dyadic coping that could lead to distance in a relationship include using sarcasm, minimizing feelings, offering support without following through, or closing off communication by not listening.

"The recommendation for families is to check in with each other about how each other is feeling to recognize the emotional state that a person is in at any point in time, not just all the things that have to be done. And then that relationship becomes a resource."



Dr. Lori Wiener, Head of the Psychosocial Support and Research Program at the National Cancer Institute

Scan to watch Dr. Wiener discuss examples of coping together



DURING TREATMENT

Entering the treatment phase of the journey often comes with a sense of hope because with a plan in place, it is easier to get a sense of how to move forward. This step of the journey is about planning, new experiences, new routines, and learning to be adaptable. Mental health needs may change throughout this phase of the journey, and ensuring that psychosocial support continues alongside medical interventions is important. This section will discuss ways that may help support you and your family during this time.



Stay connected with your community

Staying connected may not feel like a top priority, but your personal community of family, friends, and neighbors can be a major source of support while you are home and while you are away for hospital visits.



Social interactions with friends and peers are often limited when a child is going through cancer treatment, but finding ways for your child to remain in touch with friends and loved ones is a critical step in helping them maintain positive mental health.

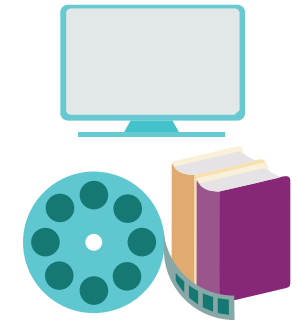
Technology can be a helpful tool to allow your child to video-chat, call, or even play interactive games with friends and family.



Encourage classmates and friends to send handwritten notes, cards, and letters. This is a wonderful way to brighten the day when your child is in the hospital, and they can be saved around the hospital room as a reminder of the love and support that exist outside the hospital.





Access educational resources

Multimedia materials for both caregivers and children are available to help explain and normalize the cancer experience, necessary procedures and treatments, and associated feelings. They should include, but not be limited to, books, handouts, videos, medical play toys and dolls, and games.



Find ways to give your child choice and control

Each child is different in the amount of information they find helpful:

-  Provide them with developmentally appropriate materials.
-  Allow them to be an active participant in procedures by helping or watching, and taking breaks when needed.
-  Create a coping plan that includes outlets and distraction techniques.
-  Taking medications at the right dose, schedule, and frequency as recommended by your healthcare team is an especially important part of getting better. Sharing the purpose of the medication where appropriate and creating a reward plan to encourage sticking with treatment may be helpful to your child. Include them in reminder strategies.

Change the focus

Distraction can be a highly effective way to pass the time and keep your child's mind focused on things they enjoy. Examples of these include:

- » Tablets
- » Books
- » Music
- » Toys
- » Pet therapy
- » Virtual reality
- » Blowing bubbles
- » Art therapy
- » Music therapy
- » Dance
- » Video games
- » Facetiming with friends or family

Learning simple ways to lower stress can be helpful for you and your child, as well. Some ideas include: deep breathing exercises, relaxation, meditation, and guided imagery. If you are unfamiliar with how to do these exercises, ask one of your healthcare team members to teach you.



Find ways to have fun throughout the journey—celebrate even the small wins!

“When we started to try to find ways to have fun, I feel like we took control of the battle... my [Little League] coach would always tell us the moment you stop having fun playing the game is the moment that you already lose. And I took that approach with this battle of cancer. And I told myself if I allow cancer to steal our joy, if I allowed it to stop us from having our fun relationship, then that would be the moment that we lose. So, we just looked for opportunities where we could have fun and create the environment in which we wanted to be instead of allowing the hospital to dictate that.”



Devon Still, father of childhood cancer survivor Leah

Scan to watch Devon Still discuss how he had to refocus



AFTER TREATMENT

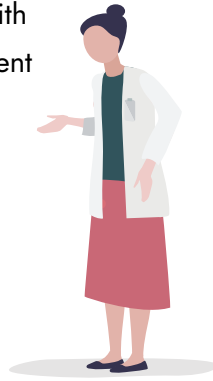
Life after treatment looks different for everyone. It comes with a new set of joys as well as new challenges. Preparing for life outside of the hospital in advance can help establish valuable routines and support networks to provide solid ground for the entire family. Staying in touch with your established hospital community as you make this transition is especially important to allow for continued monitoring of both medical and psychosocial needs.



Know that your healthcare team will still be involved

Near the end of active treatment, you and your child should meet with your healthcare team and receive a summary of the care and treatment that was received. Your team will recommend the appropriate frequency of follow-up visits (yearly at a minimum) and the tests you can expect to have done at each visit, which will include a psychosocial check-in. These follow-up visits play a key role in:

- » ensuring your child's recovery is going according to plan
- » identifying any short-term or long-term effects of treatment
- » monitoring for late effects (health problems that can appear months or years after therapy has ended)
- » helping your child learn how to begin taking responsibility for their health needs as they get older



Utilize school resources

Returning to school is an exciting and sometimes complex milestone after treatment. Preparing the school for a child's return is essential to making that re-entry smooth and successful.



- » Provide school personnel with information on your child's diagnosis, treatment, and any needs or accommodations your child may have. This can be done by you or someone from your healthcare team. Preparing the school's staff with this information can help to create a compassionate and understanding environment for your child's return.
- » It is common for children to need some extra learning support after they have gone through cancer treatment. An individualized education plan (IEP) can be set up with the school to make sure your child's needs are met. Your healthcare team can help you work with the school, if necessary, to set up an IEP.

Create a new normal

Life is never the same after an experience like cancer. You and your family have grown and changed since starting this journey. Many people look forward to "going back to normal" after treatment is complete, but rather than going back, it is important for all family members to adapt to a post-cancer treatment life going forward. You may have different goals and priorities now. You also may have a new or altered support system. It is important to acknowledge these changes and new perspectives, and how each of you may have been changed by the experience as you work to adapt as a family.

Have honest conversations

This process is not easy, but having open and honest conversations with your child and family members about their feelings and perspectives is critically important.



Be patient and kind with yourself as you learn how to establish new disciplines and routines, healthy nutrition and wellness behaviors, and new ways to interact with your friends and community.

Cope with the emotion of grief

Grief is a feeling that can be experienced throughout the journey. Finding new meaning and hope, regardless of the circumstances, is possible in your own way on your own timeline.



Support is available in the community to help your family address grief and loss, and post-traumatic stress symptoms.

Find your identity, and help your child find their identity, beyond the cancer experience.



Connect with other families like yours to advocate for each other at both local and national levels.

“Think about that each day is a gift. Because none of us knows what tomorrow is going to bring. [There is something positive] that you may be able to find from that day. It may have been a nurse smiling. It may have been a meal that didn’t come cold. It may have been that you had less traffic. It may have been a smile or a kiss. It may have been a butterfly... Being able to find some sense of gratitude for that day and to appreciate that day, because we’re not going to have that day again, could take families a long way.”



Dr. Lori Wiener, Head of the Psychosocial Support and Research Program at the National Cancer Institute

Scan to watch Dr. Wiener discuss the importance of redefining the journey



Join these panelists for a discussion on

COPING with CHILDHOOD CANCER

While no journey is the same, it can be helpful to hear from families who have been in your shoes. We spoke to parents, caregivers, and former patients just like you who are navigating the childhood cancer journey with hope that their courage and honesty would provide validation of the emotions you may be feeling and comfort as you navigate your own experience.

Visit www.copingwithchildhoodcancer.com to hear from:



Devon and Leah Still

Co-founders of the Still Strong Foundation. Devon, MAPP, MBA, is a former NFL player, positive psychology practitioner, and proud father of Leah, a childhood cancer survivor.



Gavin and Wendy Lindberg

Bereaved parents and co-founders of The EVAN Foundation, named after their son Evan Lindberg, who passed away from childhood cancer at the age of 7.



Dr. Lori Wiener, PhD, DCSW, LCSW-C

Co-director of the Behavioral Science Core and Head of the Psychosocial Support and Research Program at the pediatric oncology branch of the National Cancer Institute. Dr. Wiener also led the development of the Psychosocial Standards of Care Project for Childhood Cancer.



Stephanie Ionata

A two-time childhood cancer survivor and a member of the adolescent and young adult population, Stephanie will attend Penn State next year to become a pediatric oncologist, so she can continue her quest to help children with cancer.



United Therapeutics Oncology is dedicated to the care of children with neuroblastoma. We are honored to serve this brave community and are committed to providing comprehensive care to the families and caregivers touched by this childhood cancer.