

A Caregiver's Guide to **Supporting Childhood Oncology Families**

Developed by





About the Hayden's Hope Foundation

Cancer can strike when you least expect it.

It doesn't care where you live or how much money you have. It doesn't care how old you are or how many people love you. It's brutal, unrelenting, and, despite continued strides in treatments, it impacts families every single day.

Throughout her cancer journey, Hayden Foulon spent a significant portion of her life in active treatment. This meant hundreds of medical appointments, thousands of hours of managing chemotherapy leaving her nauseous and sick for days), and numerous in-hospital stays which were often in isolation due to her immune system & lasting up to 14 days.

For her family, this meant living on one income while mom took a leave to support her care. It meant continuing to pay household bills while adding new and unplanned costs (e.g. food and parking at the hospital). It meant trying to catch a few moments of sleep on hard couches between the sounds of machines beeping with constant worry in their minds. Between the doctors searching for a cure and the kids undergoing treatment is the Hayden's Hope Foundation.

As a young non-profit organization, our immediate focus is on:

- Oncology families in Southwestern Ontario requiring bone marrow transplant & CAR-T Cell treatment at Sick Kids Hospital in Toronto
- Oncology patients in Southwestern Ontario requiring adhoc financial support
- Oncology patients and their families in Southwestern Ontario who require mental health supports during their oncology journey

To learn more, please visit www.haydenshopefoundation.com



About the Hayden's Hope Foundation *Caregiver Guide*

When a family finds out their child has cancer, their world shifts on its axis. At Hayden's Hope Foundation, we want to support these families. And we know you do, too.

If you are asking yourself, "Yes. How can I help? What do I say? What can I do?"

Developed with the generous insight of childhood oncology families in Southwestern Ontario, **the Hayden's Hope Foundation** has created this guide to answer these very questions.

This resource is for the caregivers of the caregivers – the aunts, uncles, grandparents, friends, neighbours, and colleagues who want to provide assistance and support but are unsure where to start.

In these pages, our families have shared their lived experiences and dark moments in hope that their journey will assist others following in their footsteps. How do I know what to do?

What do I say? What can I do?

Facing the Facts:

The Seven Truths of Childhood Cancer

Before you take the first step of offering your assistance and support, take time to learn the life-shattering experience a cancer diagnosis has on a family.

Here are seven truths for nearly all oncology families.

1. Childhood cancer is unfair and unjustifiable.

Today in Canada, 10,000 children are living with cancer. Every year, 1700 children and their families are forced to face the difficult realities of a new cancer diagnosis.

Cancer is cancer, and yet childhood cancer is quite different from adult cancer. Even if a child gets a cancer that typically affects adults, they require distinct treatments. Additionally, there may be long-term impacts on child survivors due to the impact of treatments at such young ages.

There have been incredible advancements in childhood cancer treatment over the last 70 years; and yet there is much that remains to be solved.

2. Every family is unique.

What each family needs for support will be unique to their journey. This guide is a collection of research and experiences but it is not intended as a definitive guide of how to act, what to say and how to be present. We will share some of the bumps made by well-intentioned people along the way and celebrate the sources of connection and support that assisted oncology families through their arduous journey.

You know your people best; what works for some will not work for all. Our hope is this guide will provide practical ideas and tangible actions for lending support.

3. Cancer is a journey.

How a family absorbs a life-altering diagnosis can vary drastically. Some are energized into action; others feel overwhelmed with helplessness. Each family will have emotions that fluctuate, energy that shifts, and stress that accumulates. Whether the family is working through diagnosis, treatment, remission, relapse, bone marrow transplant, or bereavement, the need for support remains unchanged regardless of time or outcome.

As families experience the various stages of the cancer journey, they may need more or less physical, mental and emotional support. As can be expected, and as we will explore in this guide, the members of the family are focused on their child and not on themselves. Many explain being stuck in a cycle of energy and enthusiasm to rally against cancer and then brazenly hitting walls.

As with many tragedies, the beauty of the human spirit will shine through. In the case of a childhood cancer diagnosis, it's helpful to recognize that the initial flush of support and lasagnas may be more effectively looked at through an ongoing, more long-term lens.

Procedory Families

Today in Canada, 10,000 children are living with cancer. Every year, 1700 children and their families are forced to face the difficult realities of a new cancer diagnosis.

4. The cancer journey never 'ends'.

Oncology families continue to deal with the impacts of cancer on their family for years to come. Children, parents and anyone close to the situation will carry some form of trauma from the experience, with some needing more support than others.

5. The caregivers' primary focus is their child.

Their personal well-being is typically placed on the back-burner of priorities. They can be told they need to sleep or eat or exercise; but their priority is their child.

6. One of the best ways to show love for the child with cancer is to support their caregivers.

This entire guide is structured with the intention of sharing guidance on how to show up for caregivers

from the insider's view of oncology families. And your secondary support – big or small – can make tremendous important impact. Look for little things that will ease the pressure of their lives: cut grass, shovel snow, care for pets, do laundry. Be creative but continue to respect their boundaries.

Keep in mind that these families are living with heightened stress, anxiety, and emotion; resources – emotional, physical and mental – may be limited. Whether it's impatience, dismissiveness, or anger, they will feel it all and it may spill onto you. The caregivers from our survey admitted they could be snippy and dismissive; in hindsight, they understood the impact of people who cared enough to check in and stand by them through thick and thin.

7. Take care of yourself.

As someone who cares about the child and their family, you are going through this trauma. You will have your own repertoire of emotions and responsibilities. Be compassionate with yourself. Allow yourself the grace to make missteps along the way. Check in with yourself and remember to secure your oxygen mask first.

The Debris of Pediatric Cancer

The Seven Truths of Childhood Cancer

Hearing the word *cancer* the first time is traumatic. These reverberations will show up in multiple areas of a family's life, and may add further strain to their mental and physical well-being. By having a broader understanding of the oncology experience, this context will help you determine how you can best support and show up for caregivers.

In addition to your support, psychologists, psychiatrists, counselors, therapists, social workers, and other trained mental health professionals can be found in and out of hospital; they can offer guidance and support to you and pediatric oncology families.

The following is an in-exhaustive list of difficulties that may arise in the wake of a childhood cancer diagnosis. You will find a list below that ranks the prevalence of the stressors as identified by oncology families through our 2021 survey.



Marital / Partner Stress

As with any trauma, stress can bring people closer together or accentuate existing problems. Either way, pediatric cancer is a stressful situation placed on any partnership. Each person in the relationship will be processing the situation in their own way; this, alone will affect the nature of the relationship.

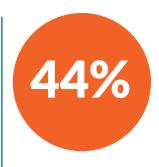
Some people throw themselves into work in an attempt to provide financially if they feel they can't do anything about the cancer directly. Others may give all of their focus and attention to the medical care of their child. The divide of emotional labour may or may not ever be discussed; whether it's being bedside, pulling strings behind the scenes or holding their child's hand during treatment.

An additional caveat to partner stress is the inability to get time alone to talk privately and be together amidst the demands of hospital life and external responsibilities.

Family Stress

The dynamics within the immediate family and their extended families will shift throughout their journey. Siblings will experience a range of emotions related to their sibling's illness and their parents' need to physically and mentally elsewhere. Siblings often feel the stress of being pulled in many directions due to parents' personal desires and expectations of how they want to be present for their kids.

The role of the extended family cannot be underplayed. Nearly half of families surveyed told us that family and friends were the biggest sources of support during their ongoing cancer journey. Some will show up and be superstars while sometimes those we think will step up end up falling short of expectation. Acknowledge that some people can only support how they are able to.





Financial Stress

In Canada, the medical cost of treatments are primarily covered. However, accessory costs continue to build during this tumultuous time. These can include hospital -associated costs such as hotel stays, parking, and travel. Furthermore, household bills and living expenses need to be paid. In response to treatment and the nature of caring for a child with cancer, one parent often stops working to assume these extra responsibilities which compounds the financial situation.

Physical Health Decline

After a cancer diagnosis, a family's lifestyle changes dramatically. The time that parents used to spend going to the gym or making healthy meals for themselves and their family is taken away. It is often replaced with more sedentary time with their child in a hospital and quick, often less healthy, meal choices. This accentuates the stress they are already feeling from managing a cancer diagnosis.

Mental stress is not a purely psychological experience – it is caught up in our physical body because **stress is a physiological response**. In addition to the impact of stress on our bodies, pre-established routines of going for walks, playing sports, cleaning our homes or going to the gym face new challenges. Moving our bodies in ways that help manage stress is not something most caregivers are, understandably, thinking about.





Monotonous Routine & Decreased Stimulation

Decreased stimulation within the hospital setting challenges caregivers' energy and moods as well as increases the incidence of obsessiveness and anxiety. The tireless beeping of monitors, continuous testing, sterile environment, and overall stress of their situation grows. The hospital routine creates an odd vacuum that has little change yet is not inherently relaxing or calm. In addition, sleeplessness caused by the distress of the situation or the lack of space and time to adequately rest creates a situation ripe for mental and physical distress.

Oncology families face significant stresses and pressure during their child's cancer journey including: trauma, depression, anxiety, obsessiveness, grief, sleeplessness, loneliness, fatigue, marital stress, financial stress and more.

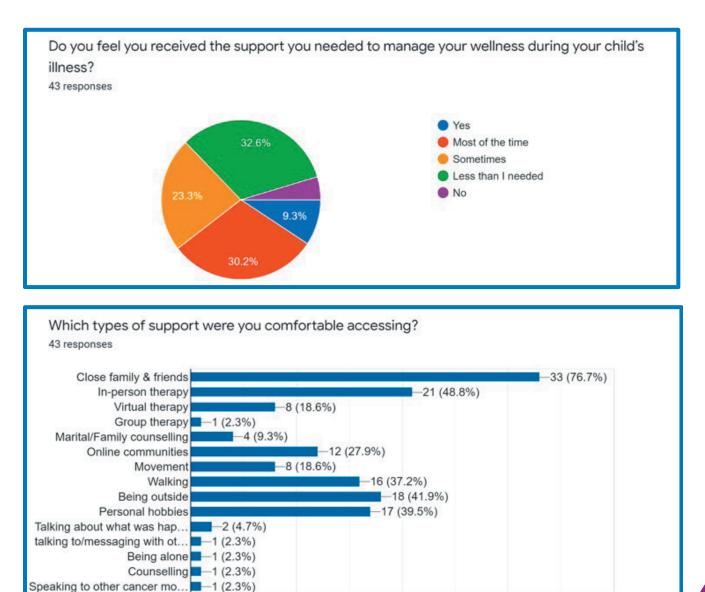




Mental Illness

Witnessing a child go through cancer is unimaginably stressful and traumatic. These feelings do not naturally dissipate over time. We might get used to them, because the experience is daily, but the stress and trauma continues to affect us.

Every single oncology family we spoke with told us they experienced mental distress throughout their cancer journey. This stress shows up in their bodies, moods and behaviours in a variety of different (and sometimes opposing) symptoms.



From HHF Caregivers Survey - January/February 2021

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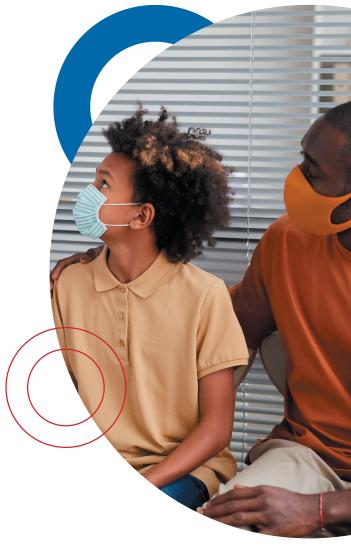
Mental health professionals can play a pivotal role throughout a family's cancer journey.

This guide is not intended to help identify *if* a family or friend is in distress. It is intended to provide a loose framework of diagnoses received by our caregivers. We hope it may prepare you to support if you or the caregivers begin to observe signs of mental illness and distress.

Loss of Identity

Neither separate or tied exclusively to the list above, many caregivers revealed that they felt a loss of personal identity throughout the cancer journey. The factors varied from being consumed by all-things-cancer, to not taking time for personal hobbies or pastimes, to the various manifestations of stress affecting how they think, feel and react.

When someone you love deeply is affected by cancer, you are forever changed. However, the aspects that make the caregivers 'them' are also still there. Connecting with these personal attributes throughout devastating challenges and stressful events – whether through people, hobbies, work, or entertainment – can help provide an anchor for them to hold.



DEFINITIONS TO NOTE * Mayo Clinic definitions

Acute Stress Disorder*: severe stress symptoms during the first month after a traumatic event

Post-Traumatic Stress Disorder*: a mental health condition that's triggered by a terrifying event – either experiencing or witnessing it.

Depression*: mood disorder that causes a persistent feeling of sadness and loss of interest; it affects how one feels, thinks, and behaves and can lead to a variety of emotional and physical problems.

Anxiety*: excessive and ongoing anxiety and worry that are difficult to control and interfere with day-today activities may indicate generalized anxiety disorder

Panic attack*: a sudden episode of intense fear that triggers severe physical reactions when there is no real danger or apparent cause

Binge behaviour*: frequently consuming unusually large amounts of food, alcohol, drugs or compulsive shopping and feeling unable to stop

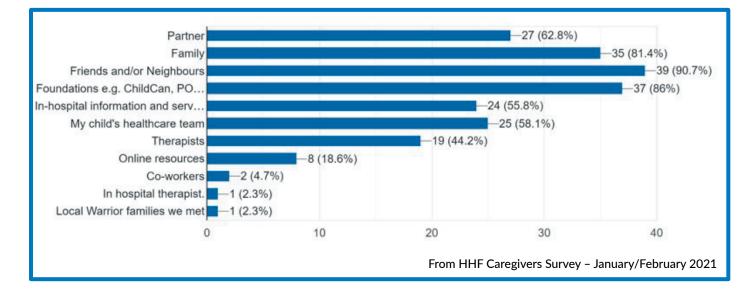


Road Blocks: What gets in the way of getting help?

When asked, caregivers told us that they did not access the support they needed for their own wellbeing for 3 primary reasons:

What they told us	What we can do
I didn't have the time or energy to seek out options.	We can be their time and energy to seek out options.
l didn't recognize what I was going through because I was only focused on what my child was going through.	We can keep an eye on them and tactfully share observations or concerns when appropriate.
I didn't want to leave the hospital bedside.	We can sit with them so they can get out of the hospital, sleep, or take a break. We can bring what they need to them.

Here's where oncology families we surveyed received the most support. Note that family, friends and neighbours (aka caregivers) are at the top of the list:



At Hayden's Hope Foundation, we know that roadblocks are a part of the cancer journey. We know you want to help bridge the gap between what caregivers need and getting them the appropriate services or support that meets it. For a full list of resources, see the Appendix in this guide.

What to Say (& Not Say!) to a Pediatric Oncology Family

When a family receives a childhood cancer diagnosis, it's natural to want to do something or say something.

Unfortunately, there are no magical words.

What needs to be heard is a very personal thing to each person and family. Knowing the right thing to say (and what not to say) can sometimes feel impossible.

Below are a few guideposts for navigating the topic of pediatric cancer with oncology families. Although missteps are a part of being human (and we've all put our foot in our mouth), we hope this will be a way we can lighten the emotional load for oncology families.

1. "Tell me everything that's going on" – Sometimes staying quiet is okay

Take the caregivers lead. If they want to talk about it, let them. If they do not, don't. Try to "read the room" and go with their flow. They may have talked to many others before you and may not want to go over every detail a seventh time that day. Or, they just might.

Examples: Embrace the silence and just be.

2. "You're so strong – you'll get through this!" -Avoid toxic positivity

Dr. Jaime Zuckerman describes toxic positivity as "the assumption, either by one's self or others, that despite a person's emotional pain or difficult situation, they should only have a positive mindset or 'positive vibes". This messaging has a way of creating shame and guilt while simultaneously dismissing their experience, feelings and thoughts.

Examples: "You're so strong" | You'll get through this. | Your strength is amazing. | Everything happens for a reason." | "Everything will be find because the prognosis is good." | "It is what it is." | "You have 2 other children so you should feel blessed." | "You're okay"

3. "Everything happens for a reason" – Avoid the positive spin

These pop up in comparative statements and sometimes carry a spiritual tone. Again, read the room – not every positive quote on Instagram is helpful.

Examples: "At least they got the good cancer." | "God doesn't give you more than you can handle." | "Everything happens for a reason." | "Heaven needs children, too." | "At least their cancer is curable." | "They are in a better place now."

4. "I was reading on Google/Facebook that...." – Avoid unsolicited advice

Don't comment or inquire about treatment in front of the child unless the parent initiates. Don't ask how they could possibly give their child chemo when there are natural treatments available. Don't ask questions for your own curiosity or to reiterate your personal beliefs. If families want to talk about treatment options, they will bring it up. If the person making the recommendation is not their primary oncologist, they do not want to hear unsolicited advice. **Examples: "Someone did _____ treatment and their cancer was cured."**



What to Say (& Not Say!) to a Pediatric Oncology Family Cont'd

5. "Will their hair fall out?" – Don't ask questions to satisfy your curiosity

It's natural to be curious and want to ask questions. But for those living through trauma and hardship, questions can sometimes be perceived as intrusive, nosy and potentially triggering. Let the parent initiate what and how much they want to share - they may open the door easily.

Examples: "Will they be better after treatment?" "So, after a bone marrow transplant he will be totally fine?" "What are you going to do when their hair falls out?" "Are they cured now?"

6. "I know exactly how you feel" – Not every experience is a "shared experience"

A desire to create connection is natural but it can sometimes result in anger, frustration and isolation – as though the person speaking couldn't possibly understand what they were feeling because they said something so disconnected. This could include venting about how tired and exhausted they (non-oncology family) are or comparing the loss of a pet to the loss of a child.

In bereavement, there is nothing similar to losing a child. Even losing a loved one like a parent or a spouse is still a different type of grief. *Examples: I know exactly how you feel.* | *I remember when I lost my grandparent...* |

7. "How did they get cancer?" -

Do not inquire, under any circumstance, about the cause of the cancer.

The causes of pediatric cancer are primarily unknown and unrelated to lifestyle and environmental risk factors. Suggesting otherwise is unnecessarily painful to families.

Examples: "How did your kid get cancer?" | "Do you think it was something you ate or suffered while your child was in utero?" | "Were they fed organic food?" | "Were they formula-fed or breast-fed?" | "Was there anything you could have done to prevent this?" | "Do you think they got cancer because they eat sugar?" | "Was this cancer from your side of the family or your husband's?"

8. "They're in a better place now" -Don't say silly things (& no, "silly" was not the first word that came mind)

One parent revealed how comparison made her feel: "Don't compare my kid to another kid you know who had this cancer and beat it. Don't tell me that if my kid is strong and fights hard, they will beat cancer. My kid is strong and will fight hard, but he has no control over the outcome of his treatments."

Also, don't tell a parent that someone they know passed away from the same cancer (and especially in front of the child) or that once treatment is over they can get back to a normal life. **Examples: "You're young and can totally have more kids." | "They are in a better place now." "I'd come visit but I just don't think I can see your child so sick."**



What you SHOULD say to Oncology Families – Six Guiding Principles

Now that you know what to avoid, here are six guiding principles to help shape what you SHOULD say to oncology families.

1. (Again) Take the caregiver's lead.

Be present. Ensure the caregiver that you want to hear about their thoughts and feelings. If they are not ready, willing, or able, ensure that if or when they are, you will be there. Sometimes a quiet coffee together can 'speak' volumes.

2. Validate their experience.

Learn about, understand and express acceptance of another's emotional experience.

3. Take time to check in with them personally.

Have they had a chance to nap? Are they eating? Do they want to join you for a walk?

4. Actively listen.

Active listening describes a reflective manner of conversing. It includes listening to hear, paraphrasing and reflecting back without judgment or advice. This can be a great tool for testing the conversational waters as well as ensuring that they feel heard.

5. Hold safe space for them to vent, cry, laugh, and be angry.

Many oncology families don't reach out to family and friends because they are concerned about feeling like a burden. Make an effort to clearly say that you want to be there and you want to hear how they are doing.

6. Recognize if they need a break from talking.

Whether it's safe words or simply feeling the temperature of the conversation, allow them an opportunity to press pause and resume another day. And then return to Step #1 another day.

How Can I Show Up?

"Let me know if you need anything."

This is something oncology families hear over and over. Yet families rarely take up the offer because: **a.** They question the sincerity of the offer; it sometimes feels like an empty sentiment or something people are "supposed" to say

b. They do not want to feel like a burden

c. They do not have the time or energy to manage, plan ,and delegate tasks that may be helpful.

Instead of "Let me know if you need anything", families appreciate people taking the lead.

Ways to turn good intentions into helpful actions:

Be direct: Caregivers told us they appreciated people taking the lead. This is especially valuable if you are aware of specific tasks that need to get done. *"I'm going to do _____ for you on ____"*.

Provide options: If you are not exactly sure what a family might want, think of a few different options so that they can politely offer which would be preferred. *"I'm going to either drop off groceries or prepared meals on Friday. What's best for your family?"*

Frame as a question: Instead of saying, "Let me know...", ask a short-term question that may assist in bringing ideas to the forefront. **"What needs to be done?"**

Be traffic control: Become the delegator. If you are very close with the caregiver, work with them to create a list of tasks and actions that would be supportive. When anyone says, "Let me know what I can do", the caregiver can simply direct them to you.





What Can I Do?

Below are some actions of love that can alleviate the mental and physical demands of oncology families. **One thing to keep in mind, though, is time.** The reality is that the outpouring of support tends to dwindle over time while the resources and energy the family has in their reserve tank simultaneously decreases. As the cancer journey continues beyond diagnosis and initial treatment, the need for support continues.

	What you can do	Did you know
Household	 House cleaning service Cleaning the house Walking pets / caring for pets Taking out the garbage Seasonal items: cutting grass, snow removal, raking leaves Set up a monthly Amazon order for household supplies like toilet paper, shampoo, laundry detergent, diapers, etc. 	While a family is managing cancer, their homes need to be managed as well.
Financial Support	 Help with bills Gift cards Fundraisers Parking passes Food vouchers Restaurant gift cards Gas gift cards Pre-order regular household items 	25% of families who have a child with cancer lost greater than 40% of their household income. 33% had to deal with housing, energy or food insecurity within 6 months of diagnosis.
 Playdates Before/after school care Taking pictures and videos at events parents have to miss Activities and gifts for siblings (in- & out-of-hospital) 		Children who have a sibling with cancer are dealing with multiple changes to their family and homelife.

	What you can do	Did you know	
Food & Drink	 Regular meal trains Groceries Dropping off meals Coffee and snacks on treatment days 	At the start, community presence is often high and meals are plentiful. However, appetites are often suppressed at this time food can go to waste. Spreading this generosity out over time could make a greater impact for the family.	
Personal Wellness Check	 Connect with them so they do not feel alone Drop into the hospital to be with their child so they feel they can mentally take a break Bring water 	Oncology families don't have the time or energy to think about taking care of themselves during these times. It is up to us to do that for them. Nurture them while they nurture their child.	
Hospital Specific	 Drop off food and drink Personalized entertainment bags Call/text Watch shows/movies together Take care of their outside world so they don't have to think about it (see Household) 	Hospital stays can be monotonous and repetitive with the same walls, the same food and the same rhythm. Try to shine a little light into the trying days by checking in and providing opportunities for socialization and connection.	
Connection	 Outings with other oncology parents Outings with friends Social media support groups Pediatric cancer fundraisers and events 	Although there is nowhere these parents would rather be than bedside with their child, it can be an isolating experience. Connecting with other adults can provide relief and support for the long haul.	
Family & Kids Gifts	 Provide childcare for date nights Favourite snacks Entertainment • Electronics Earphones / earbuds Online tv/movie memberships Online book membership Online fitness memberships Kindle • Movie passes Date night gift cards 	Bring a little thoughtful magic to brighten their day. Depending on the situation, gifts suitable for hospital stays, time at home or travel may be especially considerate.	

Apendix: Resources



We want to help take the work out of caregivers getting the support they need. As families reel with the fluctuations throughout the cancer journey, remember to meet them where they are – physically and emotionally.

Below is a brief overview of professionals and services that may be available to lend support to caregivers. By having an understanding of which services, charities, clinics and companies are available, we may be better prepared to empower caregivers to access the help they deserve.

If you have a resource to add or an edit to flag, send it to lindsay@haydenshopefoundation.com.



Connecting with Other Oncology Families

Many caregivers receive invaluable support from other families who relate to their experience: "Talking to families that were ahead of us in the journey was the best mental help we got".

Look for...Online communities, group therapy, nn-hospital families Where to find them... Social media; via other families in the hospital with them

Connecting with Mental Health Professionals



Caregivers often seek out mental health professionals while in bereavement or when their child is in remission. In hindsight, they unanimously conclude they could have used support throughout their journey. Finding the 'right fit' can take a few trials. Make sure that the relationship between the caregiver and their therapist works. If not, try someone else and don't force the rapport.

Look for...Psychologists, Psychiatrists, Psychotherapists, Counselors, Social Workers

Where to find them...

Seek out resources in-hospital, community agencies, mental health clinics, and private practice. **Some potential resources:**

http://www.psychotherapyontario.org/find-a-therapist https://www.psychologytoday.com/ca/therapists/ https://www.psych.on.ca/Utilities/Find-a-psychologist http://www.findasocialworker.ca/ON/en/default.asp

Organization	Category	Support	Contact
Hayden's Hope Foundation	 Mental Health Financial support at remote hospitals 	 Financial support for families of children with Leukemia that require treatment at remote hospitals Mental health supports for parents/ caregivers of pediatric oncology children. 	Phone # - 226-927-1872 Email – lindsay@ haydenshopefoundation.com
Childcan	 Financial support Family support Bereavement 	• Financial assistance including food vouchers, parking passes, assistance with bills, uncovered medications, funeral costs	Hospital social workers must initiate contact – ask your support team for a referral
Pediatric Oncology Group of Ontario (POGO)	• Financial support	• Financial assistance including \$ / day during in-patient and clinic days, daycare assistance for siblings, Ronald MacDonald and hotel fees, uncovered medications	Hospital social workers can provide contact information for the POGO interlink nurse
Jennifer Ashleigh Children's Charity	• Financial support	• Financial support to those who qualify for their program	Submit online application through their website
Tara Boom Houston Foundation	• Financial Support	• Financial support to those who qualify for their program	Phone: 519-631-5359 Email: info@tbhcf.com
Ronald MacDonald House	 Family support Accommodations 	• Accommodations for families to be closer to their hospital for patient treatment	Ask your hospital social worker London Phone # - (519)-685-3232 Toronto Phone # - (416)-977-0458
TLC Foundation	• Oncology Children Support	• Bringing smiles and fun to brighten your child's day while going through life threatening diseases.	Phone # - (519)-870-3833 Email – tlcfoundation1@outlook.com
Make-A-Wish Foundation	• Oncology Children Support	• Granting all children with life threatening diseases a wish of their very own!	Phone: 1-888-822-9474 or referred by a medical professional
Childhood Cancer Canada	Childhood cancer research	Research and development of new treatments	Email – info@childhoodcancer.ca
Camp Ooch & Camp Trillium	Child & Family Support	 Provides a camp program where oncology children and families can go and have a safe and fun camp experience They also provide programming in hospitals 	Phone # - 1-888-464-6624 Email - oochigeas@ooch.org

locations throughout Canada. Ask your in-hospital support staff for how to connect.

