

CHAPTERS OF
COURAGE
KNOWLEDGE & RESILIENCE IN LEUKEMIA

Volume 4:
Johannah's story

**THE HEART OF
CAREGIVING**

MEET JOHANNAH

Johannah is a partner, mother, caregiver, and counselor, guided by a deep sense of faith and a calling to support others through life's challenges. When her husband, Larry, was diagnosed with acute myeloid leukemia (AML) in 2023, her role shifted in ways she never expected. Having already devoted years to caring for her daughter, Heather, who was born with spina bifida, and raising her son Chad, Johannah suddenly found herself navigating a new chapter of caregiving. Her story is one of resilience, hope, and the strength of family.

Johannah and Larry built a life rooted in partnership, family, and quiet routines. Together, they supported Heather, sharing caregiving responsibilities and approaching life as a team. Larry was strong and dependable, always working to build a life—and a home—that would support his family, including plans for a space tailored to Heather's needs and independence.

Johannah brought warmth, care, and a steady presence that held everything together, becoming the foundation her family relied on. Whether outdoors, at church, or on their annual trips to the mountains, they found meaning in the traditions they shared. Their life was steady, meaningful, and rich with love.

“It sounds very simple, but that’s what we enjoy, just sitting outside, being together. That was our life.”



WHEN EVERYTHING CHANGED

The first signs were subtle. Larry, once always the first to help, began to slow down. Small, familiar gestures—like meeting Johannah at the car to carry her bags—quietly disappeared. It was these changes, more than anything else, that signaled something wasn't right.

The diagnosis came as a shock. Johannah was at work when she received the call and rushed to the hospital. Hearing the words “acute myeloid leukemia” felt

overwhelming—especially because it was so unexpected. Larry had always been healthy, active, and rarely sick.

In an instant, everything shifted. There was no time to adjust, only an immediate need to step into a new and deeply challenging role. Johannah found herself managing medications, coordinating appointments, handling finances, and supporting both Larry and Heather through an uncertain and difficult time.

“You go from just living your normal life to suddenly everything is about doctors and what comes next. It changes so fast.”

HOLDING THE FAMILY TOGETHER

Caregiving was not new to Johannah. For years, she and Larry had shared the responsibility of supporting Heather together. But after Larry's diagnosis, that balance shifted, and what had once been shared was now hers to carry alone. At the same time, the future they had been working toward—including the home they hoped to build for Heather—felt uncertain.

The work was both visible and invisible. Johannah managed the logistics—medications, appointments, bills, travel—while also carrying the emotional weight of keeping her family steady. She stayed strong for Larry, continued supporting Heather, and held everything together in ways that often went unseen.

She kept what she came to think of as her caregiving backpack close by, filled with the essentials she relied on each day. In many ways, it reflected the role she had taken on: always prepared, always carrying what others might need.

The journey was unpredictable. Periods of hope were often followed by setbacks, creating an emotional rollercoaster that was difficult to navigate. Some days, it felt impossible to know what came next.

“You just do what needs to be done. You don’t really think about it—you just take care of each other.”



“We couldn’t have done it without the support of our community.”



Living in a rural area added another layer of complexity, making access to care and transportation more challenging. Through it all, support from their community made a difference. Neighbors, church members, family, and their care team stepped in with help and encouragement. Johannah leaned on her faith and journaling as anchors—ways to process, reflect, and continue moving forward.

Over time, Johannah came to recognize the importance of receiving support, not just giving it. What once felt difficult—accepting help and leaning on others—became an essential part of how they moved forward, alongside small rituals like praying together, staying connected, and finding ways to preserve a sense of normalcy, even in the hardest moments.

“People just showed up for us—and that meant everything. It showed us we weren’t alone, and that gave us strength.”

Caring for someone with cancer can feel overwhelming at times.

These resources may offer practical guidance as you navigate day-to-day caregiving:

Blood Cancer United | Caregiver workbook



Caregiver Action Network | Leukemia caregiver guide



You may also find these broader support resources helpful along the way:

American Cancer Society



CancerCare



FINDING PEACE AGAIN

Today, Larry is holding steady—something that once felt uncertain. With that progress, Johannah and her family have begun to reclaim parts of life that once seemed out of reach.

One of the most meaningful changes has been building and moving into their new, accessible home they had long envisioned to better support Heather’s independence. For years, those plans had been put on hold—first by circumstance and then by Larry’s diagnosis. When the time finally came, Larry was able to regain enough strength to take part in bringing the home to life, alongside the support of their community. What once felt uncertain had finally taken shape.

The home represents more than a physical space. It reflects what they built together—Larry helping to create a place for his family’s future, and Johannah being the foundation that held everything in place. It now serves as both a literal and emotional scaffold for their next chapter.

With that sense of stability, Johannah and Larry were able to do something they hadn’t done in a long time—step away to Florida and simply be together. Sitting side by side by the pool, Johannah reflected on how far they had come—from fear and uncertainty to simply being present together.

It marked a shift—from survival mode to something softer. Space for gratitude. For reflection. Even for joy.

Caring for herself is still a work in progress, but for the first time in a long time, it’s something she’s beginning to consider again.

Caring for yourself is an important part of caregiving. These resources may help support your wellbeing and connect you with others:

HealthTree Foundation



Imerman Angels



Caregiver Action Network



“We looked at each other and said, ‘Look at us... here we are, after everything we’ve been through.’”

MOVING FORWARD

with gratitude

Through uncertainty and challenge, Johannah discovered a strength she didn't know she had. Her caregiving journey reshaped her life and perspective, teaching the value of presence, connection, and hope.

Today, she and Larry embrace a new chapter—one they built together and continue to shape, grounded in gratitude and strengthened by all they've been through. While the future is still unknown, it now holds space to pause, reflect, and find peace in shared moments.

*“You don’t take a single day for granted.
You just feel grateful—to be here,
to be together, to have this life.”*

Faithfully,
Johannah