THE HEARTBEAT

NEWSLETTER

EDITOR'S NOTE

Dear Reader,

Welcome to another edition of **The Heart Beat.**

As we find ourselves well into the latter half of the year, I hope you are taking a moment to pause and reflect on how far you have come. Life has a way of moving quickly and in the middle of chasing goals, meeting deadlines and caring for everyone else, we sometimes forget to check in with ourselves.

This month, we explore why **lived experience is expertise** and deserves recognition, reflect on the importance of **accepting help** when it is offered, celebrate **Desire Namazzi's** inspiring journey from **cancer survivor to founder of Seasons of Love**, and highlight our **"Be Kind to Your Mind"** community outreach in Namuwongo.

Thank you for reading, sharing and growing with us. We hope these stories remind you that healing is possible, community matters and hope is always worth holding on to.

HAPPY READING!
HEART TO HEART SPACES

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LIVED EXPERIENCE IS EXPERTISE AND IT DESERVES RECOGNITION

With the growth of the mental health sector comes a new and necessary conversation: **the role of People with Lived Experience (PWLE).**

People with Lived Experience are individuals who have personally lived with a mental health condition, navigated recovery, cared for someone with mental illness or survived experiences that have significantly impacted their mental wellbeing.

Their expertise is not theoretical; it is born from real life. They understand the health system not as professionals observing from the outside, but as people who have walked through it, often at their most vulnerable.

For many years, mental health interventions were designed almost exclusively by clinicians, researchers and policymakers. While their expertise remains invaluable, one crucial voice was often missing: the people the interventions were actually intended to serve.

Thankfully, that is beginning to change.

Today, more organisations are recognizing that meaningful innovation cannot happen without including the very people who will ultimately use the services, medications, technologies and policies being developed.

Whether it is designing a mental health application, developing a new medication, creating a public awareness campaign or improving access to care, People with Lived Experience bring perspectives that no textbook, research paper or clinical placement can fully provide.

Auma Rita part of the Digitalizing Psychosis team as a Person with Lived Experience at The Mental Health Data Price by APHRC.

They are often the first to identify barriers that professionals may overlook. They ask questions no one else thinks to ask. They point out language that feels stigmatizing, systems that unintentionally exclude people, and gaps in care that only become visible when you have lived through them yourself.

Their contributions do not simply improve products or services, they make them more humane, more accessible and more effective.

I am genuinely excited that People with Lived Experience are finally being given a seat at the table. However, there is another conversation we need to have.

For decades, patients have shared deeply personal stories, participated in focus groups, reviewed policies, tested products, trained professionals and shaped research all too often without recognition or compensation.

Their experiences have gone on to influence clinical guidelines, improve service delivery, redesign healthcare systems and inform groundbreaking research, yet many have remained invisible in the process.

We would never expect a lawyer, psychologist, researcher or consultant to provide specialized expertise for free simply because they are passionate about their work.

So why do we continue to expect that from People with Lived Experience?

Lived experience is expertise. It has value. It takes emotional labor to revisit painful experiences so that systems can become better for others. It requires vulnerability, courage and insight. That expertise deserves to be respected, acknowledged and fairly compensated.

This does not mean that every conversation about lived experience should be paid. There will always be moments when people choose to share their stories voluntarily for advocacy or community.

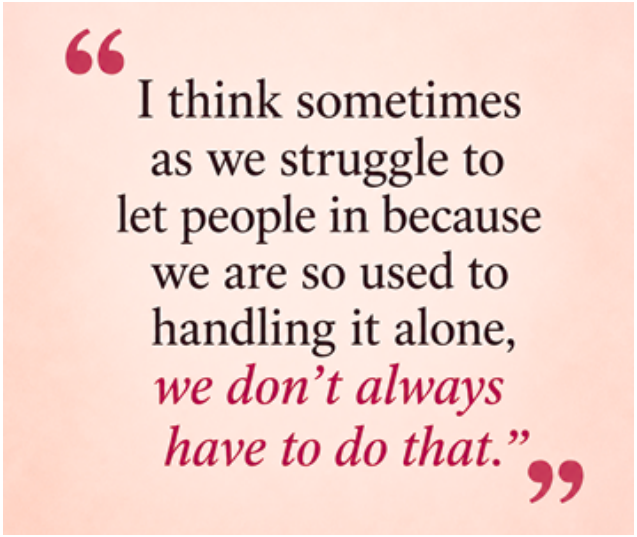
But when organisations, institutions, researchers and companies are drawing on lived experience to improve programs, influence policy, design products or secure funding, they should also budget for compensating the people whose expertise made that work possible.

BY AUMA RITA
FOUNDER HEART TO HEART SPACES.

MY WAXER TOLD ME SOMETHING I DIDN'T KNOW I NEEDED TO HEAR.

I was waxing recently, and the waxer asked how I had been. That was a hard question to answer because it had been a tough month. I started to tell her all the ways life has kicked my ass and I did not know how to lean on my own support system because I did not want to be a burden. She said to me, “Never ignore people who are willing to offer you help.”

I have a hard time with the phrase "how are you," and as someone who quickly realised that not everybody wants to hear the truth concerning what is happening in your life. I learned to be polite and give the generic answer that everyone expects. In all of that, I learned to hide my true feelings. I got so good, in fact, that I learned to hide the truth from people who actually wanted to hear it. It wasn’t until I had that conversation with my waxer that I realised maybe I did not have to be so alone.



I had made so many excuses for not opening up, saying I didn’t want to worry them or that they wouldn't understand. I went as far as keeping certain things to myself, but if help has been offered, take it. I think sometimes as we struggle to let people in because we are so used to handling it alone, we don’t always have to do that.

My challenge for you today is to accept help especially when offered. You already go through so much don’t add the burden of going at it alone.

BY DR. PEARL MIREMBE
HEAD OF COMMUNICATIONS
HEART TO HEART SAPACES

MY SECOND CHANCE BECAME SOMEONE ELSE'S HOPE

My name is **Desire Namazzi**. I am 26 years old and a cancer survivor.

In April 2020, I was diagnosed with Acute Lymphoblastic Leukemia (ALL) after experiencing multiple misdiagnoses from different hospitals. Following my diagnosis, I immediately began chemotherapy at Mulago Hospital. However, the first cycle of treatment was unsuccessful because of the aggressive nature of the cancer.

My doctor then explained that we needed to intensify the chemotherapy to eliminate the cancer. He also recommended a bone marrow transplant, as it would give me the best chance of survival and prevent the cancer from returning.

With this new reality, my family and I began preparing for the next phase of my treatment. In June 2020, we started fundraising to raise **USD 80,000** for my transplant in India. Despite the challenges brought about by the second COVID-19 lockdown, we were blessed with overwhelming support from friends, family, and well-wishers. Through their generosity, we were able to raise the full amount needed for my treatment.

By the end of July, my doctor confirmed that my body was free of cancer cells, meaning I was ready for the transplant. In August, I travelled to India with my mother and aunt to begin this next chapter of my recovery.

At the end of August, I was admitted to Indraprastha Apollo Hospital in Delhi, where I underwent radiation therapy. On **4th September 2020,** I received my bone marrow transplant. My mother selflessly donated her bone marrow, as she was a 50% match.

After the transplant, we were advised to remain in India for 100 days so that my doctors could closely monitor my recovery and ensure that my body accepted the donated stem cells. The journey after the transplant was not easy. I experienced numerous side effects that affected me physically and mentally while also struggling with the emotional difficulty of being away from home.

Thankfully, in December 2020, we returned to Uganda, and I continued my journey towards full recovery.

Today, almost five years later, I am cancer-free, happy, and healthy. Looking back, I am incredibly grateful to my family, friends, and every person who supported me throughout my journey. Their kindness, encouragement, and generosity played a major role in my recovery.

My experience with cancer changed my life completely. It changed my perspective, my goals, and even what I wanted to pursue academically and professionally. I now aspire to become a psycho-oncologist, using my personal experience with cancer and my education in psychology to support others going through similar experiences.

My battle with cancer did not only change me; it gave me a purpose. It inspired me to start a non-profit organization called Seasons of Love, which provides psychosocial support to low-income families of children battling cancer at the Pediatric Hematology and Oncology Ward at New Mulago Hospital, the same place where I received my treatment.

During my own treatment journey, I witnessed the struggles many underprivileged families faced while caring for their children. Starting Seasons of Love became my way of giving back and extending the same support and kindness that carried me through my own battle.

Through the organization, we support families by raising funds for transportation for those who cannot afford to travel to and from the hospital for treatment. We also provide essential items such as food, clothing, toys, and other forms of support to help ease some of the financial and emotional burdens these families experience.

I hope for a future where I can support as many children with cancer and their families as possible. I see this as my second chance at life, and I am determined to use it to create a positive impact and inspire hope in others.

Life is short. Don't take it too seriously.
But also live like tomorrow is your last day.

BY DESIRE NAMAZZI
FOUNDER SEASONS OF LOVE

“BE KIND TO YOUR MIND” BRINGS HOPE TO NAMUWONGO SLUMS.

On Friday, 26th June 2026, the non-profit organization **Let’s Talk Mental Health** successfully held an impactful mental health outreach program themed **“Be Kind to Your Mind”** at the offices of **Touch The Slum** in Namuwongo, Kampala.

The event, organized in collaboration with **Touch The Slum** and **Heart to Heart Spaces**, brought together teenage mothers and other young people from the Namuwongo community in Kampala. Participants engaged in open conversations about mental wellness, selfcare, and overcoming the unique challenges faced by young people living in informal settlements.

Heart to Heart Spaces was represented by Zoe Zaramba and Nuwagaba James, who joined facilitators from the partnering organizations in creating a safe and supportive space for participants. Activities included interactive sessions, creative expression exercises, and practical tools for managing mental health.

James and Zoe facilitating the sessions at “Be Kind to Your Mind Offices”

The outreach underscored the importance of community based mental health support, especially for vulnerable groups such as teenage mothers. Organizers emphasized that kindness to oneself is the first step toward healing and empowerment.

Let’s Talk Mental Health, together with its partners **Touch The Slum** and Heart to Heart Spaces, continue to demonstrate that mental health conversations are essential in transforming lives within Uganda’s urban slums.

The organizations plan to sustain this momentum with follow up sessions and ongoing support for the young people who attended.

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BY JAMES NUWAGABA
HEAD OF MENS MENTAL HEALTH
HEART TO HEART SPACES