Bridging the Gap: Why Lived Experience Is Essential in Palliative Care for the Unhoused

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Key Takeaways

- People experiencing homelessness face unique challenges that affect their ability to access equitable palliative care.
- Support workers who have lived experience are essential to bridge the gaps and overcome the barriers that exist for both clients and clinicians.
- Investment in lived-experience workers is needed to sustainably bridge the gaps in support for people experiencing homelessness.

Abstract

Told through the lens of a care provider with lived experience, the stories of Carrie and Bobby highlight how many of the most vulnerable people in our communities are expected to fit into a system that was not built for them. Lived experience matters to the person receiving care and the person delivering care; it matters to a system in need of effective, timely efficiencies; and it matters because dignity and respect are central to humanity. This article explores how integrating lived understanding into the care and caring experience in deliberate, strategic and meaningful ways is the missing piece needed to fill the "cracks" that so many often fall through. This powerful collection of stories, insights, wisdom and practices offers a bridge to connect with people who are hardly reached by our healthcare system.

Introduction: Compassionate Human Connection

As an outreach worker on the Palliative Advocacy and Care Team (PACT), my role (and my passion!) is to support people in accessing the care they need and deserve. PACT is a program led by Hospice Northwest and NorWest Community Health Centres in partnership with several other organizations. Located in Thunder Bay, Ontario, we are one of the 23 communities that participated in the Improving Equity in Access to Palliative Care collaborative.

I am an individual with lived experience. The intentional hiring of individuals with lived and living experience is relatively common in community health settings, less so in palliative care. At this point in my own life, I had been on my sober journey for about 10 years and working with the vulnerably housed for eight years.

I provide a leadership role in our community and currently chair biweekly PACT meetings. These meetings bring together palliative care doctors, nurses and nurse practitioners, homecare providers and organizations working with the vulnerably housed across the city of Thunder Bay, creating a space where we can problem-solve and make sure that no one falls through the cracks. These meetings are an important aspect of PACT's work, a safety net in a system that is not designed to serve the clients I see every day.

As an outreach worker on the team, the days are rarely the same. I support clients in accessing radiation or chemotherapy through our cancer clinic; I go to tent city or our local shelters to ensure clients get to appointments; and I do things such as help individuals access food. I support the whole person on their journey, advocating for their needs and wishes, respecting their choices and helping bridge the gap between health, housing and other social care providers.

In addition to the direct care and impact on clients, my role within the PACT team creates benefits often overlooked in the broader healthcare system – both time and resources are saved. Palliative care doctors and their staff have direct access to me whenever they need help, allowing them to check in or ask for

immediate assistance. For example, if a client has a critical appointment coming up, the team can reach out to me, and I can help ensure that person gets there. We all work together to form a network that goes beyond the traditional healthcare system, providing support and access that is timely, effective and safe.

For many of these individuals, my role may provide the only stable, compassionate relationship they have, offering emotional support and dignity as they navigate a palliative diagnosis. Some of the ways I build these relationships include transporting to appointments, providing support during appointments, connecting with food resources, housing, helping with obtaining identification, addressing any legal and financial issues, all while trying to rebuild trust with healthcare workers. I do whatever I can to make people's journey as smooth as possible.

Having a lived-experience worker in this position is critical. Not only do we offer valuable insight into a client's needs, but we also prevent more costly interventions such as emergency room visits or ambulance calls. When a client is in crisis, rather than the automatic response being a 911 call, my team and I can address the issue with the right care, avoiding unnecessary hospitalizations and allowing us to handle the situation in a more personalized and cost-effective manner.

In this article, I share the stories of Carrie and Bobby as examples of the ways that people with lived experience can bridge the gaps in our healthcare system, making it easier for people to get the care that they need and deserve.

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Carrie's Story: The System Was Not Built for Her, so We Built a Bridge

The first time I met *her*, she was struggling. She had bladder cancer, and it had already spread to her bones. She was trying to get help but kept missing appointments. Not because she did not care, but because she was homeless. No phone, no stable place to stay – just couch-surfing and trying to survive.

That was not her whole story. Carrie was more than a diagnosis or a medical condition; she is a person, a human who has a story and experiences that have made her the wonderful human that she is. Two years earlier, she lost her son – he was murdered. And that kind of grief? It does not just sit quietly in the background. It takes over your life. She started using more, partying harder and doing anything to escape. And really, who could blame her? Her parents gone, she felt alone in the world, drowning in grief and now cancer was coming for her too.

When I met her, we clicked right away. I think this was because I was open about my past. There is great power in sharing our stories, sharing how our struggles and successes have impacted our lives. When we share our stories, we share more of ourselves and, in doing so, can build trust and break down barriers to care. It acknowledges our own humanity, and although we can never walk in someone else's shoes, we can relate and be in relation to one another. She knew I was not some outsider trying to "fix" her – I had been there. And it turns out, her son had been friends with my daughter, so there was that connection too.

She was one of the kindest people I had ever met. The kind of person who would give away her last dollar if someone else needed it more. She did not have much, but whatever she had, she shared. Even when she was in pain, even when life had kicked her down over and over again.

Without the PACT collaboration, Carrie might have gone without the care she needed. Instead, we were able to find a way forward together.

Since then, I have been able to take her to and support her with almost all of her medical appointments. By sharing some of my own experiences with addiction and homelessness, I have gotten her trust and we have built a relationship. Carrie has told me that she would not be here if it were not for Dr. Bezanson (the PACT physician) and me.

Carrie's story highlights how inaccessible care can be for people without stable housing. It is built around assumptions and processes that do not stand true for everyone and, in some cases, exclude individuals from accessing care. After Carrie's nephrostomy tube surgery, she was discharged "home" – except she had no home, no bed of her own. She also had no vehicle, no income and no way to get to follow-up care. Appointments were made for her, and notices were sent by mail – mail she would never receive because she had no fixed address. At every step, the system assumed stability she simply did not have. Without PACT stepping in, she would have been left to navigate a system that was not built for her reality.

While we have helped her get to her appointments, found her a temporary place to stay and have tried to untangle the mess of her finances, it has not been easy. The system, as it is, made everything harder than it needed to be. Challenges with clear communication with social assistance/housing, paperwork and phone calls to multiple entities, including a lawyer, banks and government agencies, with more paperwork and navigation that was challenging for me. I cannot begin to imagine trying to do that on your own with a cancer diagnosis, homeless and phoneless. Nevertheless, she is fighting through it, and we fight alongside her.

Bobby's Story: Trauma From the Past Can Inadvertently Close Doors; With Help, They Can Be Reopened

Then there was him. Bobby had cancer too, but that was not the biggest thing on his mind. He was living in a shelter, and he was a substance user and drinker – his focus every day was survival. Finding his next fix, managing withdrawal, just getting through another day ... Cancer? That was a distant problem compared with the immediate ones.

When doctors recommended radiation, Bobby agreed – at first. But after his first session, he told me he was not going back. No way. Turns out, they had to strap him down to keep him still for the treatment. And for Bobby, that was not just uncomfortable – it was traumatizing. It brought back memories of the days he went to residential school. The feeling of being trapped and powerless. He would rather die than go through that again.

If our team did not exist – that might have been the end of his treatment. The healthcare system is not designed to account for something like this. No one would have asked him why he never came back – they would have seen him as a no-show for his next radiation and considered him non-compliant, and he would have been discharged. Because I was there, because I had built trust with him, he confided in me what he had experienced in residential school, a terrifying experience. I took that information back to our team. A palliative care doctor on the team took that information to the radiation department, explained the situation and asked, "Can we do this without strapping him down?" They said yes.

This small adjustment – something that would not have happened without our advocacy – meant Bobby finished his treatment. We got him into a managed alcohol program (MAP). Instead of drinking whatever he could find, he was given measured doses of alcohol on a schedule with nurses monitoring him. He was in a safe environment, his health stabilized and eventually, he moved into long-term care. His quality of life improved dramatically.

Bobby's story illustrated the importance of those working in the healthcare system having the power to advocate, remove system barriers and problem-solve. When we work alongside individuals, listen to them, hear them and work to understand their experience, we can achieve person-centred care and, patient by patient, we can transform the way the system works. Without this advocacy and system navigation, where I could be a bridge to the healthcare system to support individuals whose needs are often ignored, Bobby may not have finished radiation. He might not have made it into the MAP. He might not have gotten into long-term care. The system was not built for him, so we had to build a bridge: the PACT team.

How to Make the System Work for the Unhoused

Carrie's story. Bobby's story. They are not unique. I see this every day. The healthcare system is designed for people who have housing, family support, a phone, and a way to get to their appointments. The system is built on the idea that everyone has access to the same resources and all patients can follow the same plan. But for people who are unhoused, that is just not the reality.

This is how the healthcare system is failing them:

- *Missed appointments = lost care*. If you miss too many appointments, you are taken off the list. But if you do not have a phone, how can you confirm? If you do not have an address, phone or regular access to a computer and e-mail, how do you get appointment reminders? The system punishes people for not having stability. It does not have to be intentional to cause harm.
- *Transportation barriers*. Most people take for granted that they can drive, take a bus or call a friend for a ride to the hospital. But for someone staying in a shelter with no money, no car and no network, just getting to an appointment can be impossible.
- *Medical trauma and mistrust*. Many unhoused people have had awful experiences in hospitals – being judged, ignored or treated like they do not matter. Some have been through other traumatic institutions such as residential schools or prison. Walking into a hospital can feel like walking into enemy territory. Hypervigilance and the expectation of a negative outcome can cause a small misunderstanding to escalate exponentially. Trust is everything with this population.
- *Harm reduction is palliative care*. You cannot separate harm reduction from palliative care for unhoused people. Many are living with chronic illnesses, pain and a terminal diagnosis, all the while still actively using substances. If we do not meet people where they are, if we expect them to be "clean/sober" before they get care, then they will not get care at all. Everyone deserves compassion and access to care.
- *Dignified end-of-life care*. Many unhoused individuals die alone without support. A support worker with experience of homelessness, substance use and/or mental health diagnoses is the missing piece in bridging the gaps in healthcare. Trusting their decisions without judgement or stigmatization, allowing for connection and clear communication between community members and healthcare workers, a deep understanding of the barriers that exist, an ability to advocate for clients' needs and understanding the unique context in which they live – that is the value of lived experience.

Lived Experience Is the Missing Piece in Healthcare

This is where people like me come in. This role – people with lived experience, who can work within healthcare and act as a bridge between the system and people who fall through its cracks. I walk beside vulnerable community members, navigating complex and concurrent systems and diagnoses in a way that I wish someone had been able to for me.

Why does this matter?

Because people like Carrie and Bobby will not always open up to a doctor. However, they will open up to someone they know who has been there. Someone who understands survival mode, withdrawal, the absence of safe friends or family and someone who knows what it is like to live in a shelter. Trust is the difference between someone continuing treatment or walking away.

Lived-experience workers understand that navigating the health system is difficult. They may know what it is like to lose your identification, your phone, your housing, your sense of safety – all at once. I know this. I have lived this. Most doctors and nurses – no matter how much they care – often do not know what it is like to navigate the world without stability. When we bring in people with lived experience as members of the care team, we bring perspectives that are often not present in other team members. Diverse perspectives are essential to ensuring that more people receive care and that access to care can happen for all.

Without us, palliative care will remain a system designed for housed people with support networks. Unhoused people – some of the most vulnerable patients – are left behind. This is not just about making the system better. It is about opening a door and making it work for people who have been ignored for too long.

Policy makers need to recognize this. Lived-experience workers should not be an afterthought or a nice addition to a team – they should be standard in healthcare settings that serve unhoused people. They are the missing piece. The bridge. If we want real equity in palliative care, it is time to sustainably integrate that bridge into the healthcare system itself.

By acting as a bridge between vulnerable clients and the healthcare system, we are not only improving their quality of care but also contributing to long-term cost savings. With fewer emergency calls and better continuity of care, we reduce the strain on emergency services and allow our palliative doctors and healthcare professionals to focus on proactive care rather than reactive crises. I have no doubt that the money saved by reducing emergency interventions far outweighs the investment in having a lived-experience worker on the team.

While I know it is important to highlight the "cost effectiveness" of this model and the positive implications for the entire healthcare system such as reduced emergency visits and hospitalizations, my personal reason for advocating for more roles such as these goes beyond the numbers. For me, it is about ensuring every person, regardless of their housing status, receives care rooted in compassion, respect and dignity. No one should have to face serious illness or end of life alone without support or comfort. These roles are the bridge between medical care and the human connection that everyone deserves. HQ

About the author

Julie Diner works as a harm reduction support worker at Norwest Community Health Centres, Thunder Bay, ON. Born and raised in Thunder Bay and a mother of three, Julie has been working with the city's most vulnerable for the past 10 years at the Shelter House and NorWest Community Health Centres, Thunder Bay, ON. She is a facilitator of the St Elizabeth's Curriculum on Palliative Care for front-line workers at Hospice Northwest, Thunder Bay, ON. In her spare time, Julie is a dedicated member of Thunder Bay's recovery community and enjoys staying active.