



## Amr – Lived Experience Advisor for the Disability and Cancer Project



Amr knew they needed to see a doctor – they just didn't know how to find one.

The 22-year-old migrant had never known what a GP was when they began to feel unwell.

“I grew up in an underdeveloped region and had never been to hospital in my country of origin. So when I started to get sick here, I had no idea how to seek medical help.”

Amr is also autistic and has learning disabilities, which added extra layers to their challenges.

“I didn't know how to proceed in new social situations. Even after I figured out where to go to, I couldn't think of what to do or say after I walked through the door. I am not great at communicating in stressful situations, and I lacked the English vocabularies to explain what was happening to me.”

Amr waited for as long as they could, but as time went on their health got worse, to the point that they were in constant pain and could not pass any bowel motions or eat.

“It took me a year to figure out how to see a doctor. But when I saw them, they didn't really understand what was wrong and no one took me seriously. They all thought I was just looking for excuses to escape my exams.”

“Eventually I went to the ED and refused to leave. They finally did some endoscopy and found that I had cancer.”

Despite knowing they had cancer, Amr was relieved they had an answer.

“It was really lucky that I somehow figured things out and had the courage to advocate for myself at that crucial time. Normally, I would be too confused and shy to make such demands or cause any trouble.”

“It felt like if I took one wrong step, I would not have survived.”

Amr had urgent surgery and then went through a rigorous treatment regime while studying full time. It was especially difficult for them, as they had no family support and no stable place to live.

“I was homeless for a period and shifting every few months. Following some treatments and medical procedures, I would be told someone needed to pick me up, but I often didn't have anyone and ended up taking the bus.”

“After surgery I would be advised not to lift anything heavy for a few weeks, but I had to get groceries and carry them home somehow, and a few times I had to move accommodations within days after a surgery.”

“My medical team was lovely, and the youth workers from CanTeen really helped me get through the hardest part of treatments. But a lot of the time I was extremely anxious and lonely with no one to talk to.”

Amr’s invisible disabilities are often unnoticed and overlooked.

“People often do not believe that I’m disabled or understand what it means. Even after I explicitly disclosed that I’m autistic and I prefer written communication, medical professionals would still often refuse to read my written notes and insist that I should speak and ‘overcome my shyness’.”

“Things that are common knowledge for neurotypical people do not come naturally to me, and I had to figure everything out by myself and learn very fast. I had to keep track of everything and take care of myself, which has always been very hard for me. But there was no support for that.”

As a migrant Amr was often made to feel unwelcome and a burden to the country. At their lowest point, they did not seek medical attention when they needed to and thought about ending their own life.

“Many times I was told by people, sometimes by other patients, service providers and even some medical professionals that ‘New Zealanders’ are dying because migrants like me were ‘cheating’ and ‘stealing’ their medical resources. Some even told me that I should go home and die there instead.”

“For many years and even now still, I suffer from this mixture of internalised ableism, xenophobia, and racism. I often worry that I took too much space and feel guilty that I do not deserve to be here or be alive.”

After a gruelling period of treatment, Amr’s cancer was in remission. They struggled for another few years to get back on their feet and eventually moved on to study law and began advocating for the rights of asylum seekers, refugees and migrants living in Aotearoa.

Amr decided they wanted to work with Te Aho o Te Kahu to help improve the experience of people from marginalised communities going through the cancer system.

“Being from a minority background, whether it’s our ethnicity, immigration status, being LGBTQIA+ or disabled, our voice is often ignored and deemed ‘out of scope’. I refuse to let my experience be irrelevant and unspeakable.”

“There were no resources or support that were designed towards my situation, which made the experience so much harder. But now we are raising awareness and building knowledge and support on these issues and we hope to bring changes.”

Amr says their entire life changed following their diagnosis, but they are grateful to be able to make the most of life now.

“I have learned to go with the flow, wherever things take me I try and make something out of every situation I get into. Life isn’t a straight line.”