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UCT graduand defies invisible disability to champion palliative care as a human right



Huyaam Samuel

Photo: Supplied

When plagued by an invisible disability at the age of 11, Huyaam Samuel's life seemed to have reached a *cul-de-sac*.

Her condition was characterised by constant pain, fatigue, spasms, joint instability and frequent dislocations, with some specialists dismissing her symptoms as attention seeking or her mother being overprotective as she "looked normal" and "didn't seem in much pain".

After eight years in this predicament, it took visionary paediatrician and University of Cape Town (UCT) alumnus and senior lecturer Dr Michelle Meiring, a trailblazer in paediatric palliative care and founder and CEO of Paedspal, to diagnose Samuel with pseudo-

achondroplasia. Meiring fundamentally changed Samuel's care and her life, as she was by then dependent on mobility aids and, ultimately, a motorised wheelchair as her joint stability plummeted.

"Being both her patient and mentee transformed my life. What stood out most was the sense of empowerment it provided. Palliative care acknowledged the reality of my condition but reminded me that my life is not defined by it."

Before the diagnosis, Samuel describes her situation as having been "deeply frustrating". "I knew what I was experiencing, yet was not being heard," she said.

Today, Samuel is a master's in industrial organisational psychology graduand, an assistant lecturer within that department, and contemplating her PhD topic. She also loves to relax with a greenbelt walk or run when she is not with family and friends, or unwind with a good series. She also has her sights firmly set on an academic career.

Samuel later became a vocal advocate for the empowering, life-changing force that is effective palliative care, and served as a PatchSA Youth Ambassador and global ambassador for the Worldwide Hospice Palliative Care Alliance, addressing the World Health Organization executive board session, among other highlights.

Grateful

"Growing up, I always aspired to study at the number one university in Africa, and I worked hard throughout high school to be accepted into UCT."

Samuel has since been recognised by the Nurturing Emerging Scholar's Programme (NESP), which identifies postgraduate students who have shown academic ability and are interested in pursuing an academic career. It's an honour that has shaped her thinking around a potential PhD topic and provided mentorship and support on her academic journey.

"I am especially grateful to be mentored by incredible individuals in industrial organisational psychology at UCT, who have shaped my academic and professional growth. The award has opened doors to training, research and teaching experiences that continue to strengthen my career."

Encouragement for other students living with a chronic condition

Samuel says living with a chronic condition has certainly shaped her academic journey. It's meant navigating chronic pain, fatigue and uncertainty while balancing demanding coursework, research and, more recently, teaching responsibilities.

"At times, it challenged my confidence and required me to adapt my routines and manage my energy carefully, especially as mentally I could keep up, but physically my body often could not." She is especially grateful for support from the School of Management Studies as well as the Disability Service, which played a major role in helping her overcome challenges and continue to pursue her studies confidently.

Today her care is managed by an adult pain management team under the guidance of Professor Romy Parker, the director of UCT's Pain Management Unit. Professor Parker focused on empowerment through physiotherapy, hydrotherapy and psychoeducation, teaching Samuel how to manage her condition by treating symptoms, and building long-term strength, confidence and independence.

Her advice to other students? "Challenges can become your greatest source of strength, teaching you discipline, empathy and perseverance, qualities that will serve you far beyond the classroom."

Palliative care is a basic human right

Living with chronic illness has given her a skillset and perspective that many peers do not have, pushing her to mature faster and manage her time and energy with discipline.

Her real turning point came when she finally found Dr Meiring, who took her teenage symptoms to heart, and fundamentally changed the trajectory of her care and pain management. "It helped me conserve my energy for what really matters, engaging with people, following my passions, and proving that resilience and aspiration are possible, even with health challenges. Palliative care was about equipping me for the present and enabling me to shape a future that is still mine to define."

Her experience developed in her a deep responsibility to advocate for palliative care, particularly in South Africa where many patients and families continue to suffer without support. "Advocacy is deeply personal for me. I know first-hand what it means to be heard, believed and supported, and I want that for every patient and family facing similar challenges. Universal access means no family has to face these challenges unsupported, and every individual can live with greater comfort, dignity, and hope at every stage of a life-threatening or life-long illness.

"To me, palliative care should never be a privilege. It is a basic human right."

Samuel says that her mother and sister stood by her through it all. "Aside from God, I owe everything to them for their perseverance, tough love and sacrifices, adapting our home, assisting with my academic career, fighting to find answers, and encouraging me to keep going when no one else believed I would get better. Without their unwavering support, I wouldn't be where I am today."

Teaching at her alma mater

Samuel currently serves as a contract lecturer in organisational psychology, where she also supervises honours research projects.

"It feels incredibly meaningful teaching students in the very classrooms where I once sat. It's a full-circle moment: a chance to give back to the department that shaped my journey, while helping to inspire and guide the next generation of industrial organisational psychology students."

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