



# Engaging Ethics at UHN

## Introducing Jess du Toit

Jess du Toit is the Department's current Ethics Fellow. She is originally from the beautiful city of Cape Town, South Africa, where her long-standing interests in animal ethics, bioethics, and bioethics consultation were first piqued. Jess completed a Bachelors and a Masters degree in Philosophy at the University of Cape Town before moving to Canada in 2019 to pursue a PhD in Philosophy at Western University.

Jess's PhD dissertation focused on ethical issues at the intersection of paediatric research ethics, animal research ethics, and animal ethics more generally. Her research interests within bioethics are very broad and include vulnerability in research, ethical issues that arise in the context of caring for older adult populations and those with eating disorders, as well as the fair allocation of scarce healthcare resources. And while she plans to continue with the work she began during her PhD, she is currently doing her best to work with all six of UHN's bioethicists to get the most from the myriad unique opportunities at UHN.

In addition to her soft spot for bioethics, Jess is a keen runner and loves a good cup of tea. She also *really* loves dogs.

Jess represents the last Fellow under our partnership with Unity Health. Next year we plan to have a Fellow as part of our new UHN Fellowship program.

(Photo of Jess by Tracy Isaacs from her blog: <https://veganpractically.com>)



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### Of interest

- TIER Event on Ethical Implications of AI in Care and Education
- Transplant Ethics Rounds

## Welcome to West Park Healthcare Centre

West Park became the newest member of the UHN family on April 1st. As a consequence of this union, our network can now boast that it contains Canada's, and perhaps the world's, leading rehabilitation and complex continuing care system. Some West Park staff are newcomers to the family, but others have long-standing connections to UHN. We look forward to working with you all. We send a special greeting to bioethicist, and old friend, Maria MacDonald who will continue to support West Park teams for the next few months to ensure that the transition proceeds as smoothly as possible.



## Sr. Director's Corner

Spring is in the air and Accreditation is around the corner for various UHN programs. Clinical teams at Princess Margaret, Toronto Rehab, and the Toronto Western Family Health team have been readying themselves for surveyors and preparing to showcase the good work that they do.

Although all of this comes with an equal measure of anxiety and excitement, it's also an opportunity for a refresh and reminder of our policies, procedures, and practices. Lately, members of the Ethics Department have had the pleasure of responding to a flood of requests for in-services and we've been collating information for the surveyors' packages which highlight our frameworks for ethics consultation. Of particular relevance is our **IDEAS<sup>2</sup>**

framework which invites participants to:

**Identify relevant facts, preferences, and context** (including law, policy, culture);

**Determine values:** ask which principles or values support available options;

**Explore options:** ask which are the most defensible, achievable;

**Act and Evaluate:** make a plan, identify accountabilities, set timeframes;

**Standing:** ask who has standing in the case (patients, families, team members, others). Who should be part of decision-making?

**Story:** remember that every narrative is told from someone's point of view. Notice which stories are being heard, and which are not heard, or are in need of amplification or elaboration.

For more detail see our webpage: [Frame-works | Bioethics \(uhn.ca\)](#)

*"Act as if what you do makes a difference. It does." — William James*

The Institute for Education Research (TIER) is teaming up with Elsevier to organize a panel event:

### Ethical Implications for AI in Care and Education:

#### What we know and what we want to know

June 26th 2024, from 2:00-4:00pm at MaRS (CR 3)

This event will be *in person* only. The panel consists of experts on AI in healthcare and education, including UHN's Dr. Jennifer Bell, Rhett Alden (Chief Technology Officer at Elsevier), and Dr. Atoosa Kasirzadeh (philosopher of science and AI, and an applied mathematician).

Register here:  
<https://forms.gle/pbHhVwQCgZx7J2Ws9>  
Seats are limited.

## Meet Our Team: Jennifer A. H. Bell

Jennifer A. H. Bell is the Princess Margaret Cancer Centre bioethicist and is cross-appointed to the Department of Supportive Care, Princess Margaret, as a scientist. Jen also acts as the research lead for our Ethics team. Her own research addresses ethical issues at the frontier of cancer care. Innovative discovery, artificial intelligence, and breakthrough therapies are emerging sources of hope for people with cancer. These advances raise significant ethical issues that health systems, professionals, patients, and caregivers must navigate, such as ensuring equitable access, safeguarding patients from known and potential harms, and avoiding bias and discrimination. Recently Jen published a perspective in the journal *Blood*, detailing an ethical approach for equitable allocation of limited cell therapy cancer treatment.

Jen's research partnerships include collaborations with the Princess Margaret's Cellular Therapy Program, Cancer Digital Intelligence, Supportive Care, and the Institute for Education Research. Nationally she has partnered with such bodies as the Canadian Cancer Trials Group, the Canadian Partnership Against Cancer, the Canadian Cancer Research Alliance, 3CTN, and BioCanRx. She is currently leading a four-year national study jointly funded by the Social Sciences and Humanities Research Council and Genome Canada exploring public perspectives on the ethics and social accountability of next generation cell and gene cancer therapies in Canada. Jen leads the Ethics and AI in Healthcare Work Journal Club, co-hosted by TIER and Ethics. The club brings together learners, healthcare providers, scholars, AI developers, or anyone interested in ethics and AI, to discuss academic articles that highlight ethical aspects of AI in the context of healthcare, research, or education. (To receive notice of meetings, email [Christina.German@uhn.ca](mailto:Christina.German@uhn.ca).) Jen will be a panelist at the upcoming TIER event on ethical implications for AI in care and education, see sidebar.





Photo by [Inbetween Architects Jerome Chagnon](#) on [Unsplash](#)

## What Does an Elephant Look Like?

An ethics consultation in rehabilitation or acute care often resembles a multi-layered onion of ethical complexities given the many perspectives involved. We do well to collaborate with key clinical team members—by eliciting their perspectives and by advocating for the inclusion of the patient’s voice—and yet, we might do even better by asking, *What does an elephant look like?*

This observation is offered in response to the image of several people on a scaffold, who view the animal through individual frames. (See Charles Vorlet’s wonderful image here: [Context Matters. Illustration by Christophe Vorlet. - samim.](#)) Imagine if none of them knew what an elephant looked like and had to describe the animal they saw. They would likely stop at descriptors of each part visible through their frame: a tail, a foot, a tusk, an ear.

Ethics consultation aims to bring together all of those involved in a case to help them piece together perspectives, glimpses, insights, derived from our many identities and ways of knowing and being in this world. This allows us to reimagine ethical concerns and find defensible approaches for dealing with dissonance or disagreement. Engaging in this exercise not only embeds equity, and creates space for all voices to be heard, it also provides distance for those who may be too close to a particular patient’s care and can help them to avoid the temptation to interpret fluid aspects of the situation as “facts.” It reminds us that each perspective is but one layer of the proverbial onion.

Our experiences shape how we co-construct our realities. Even when the only way forward involves choosing the best of a range of undesirable options, ensuring that we share an understanding of context can be crucial for knowing that we did everything we reasonably could. Taking a moment to ask “*What does an elephant look like?*” can prevent us from spiraling into moral distress and disillusionment.

Context matters, and together we can make an effort to be inclusive within safe moral spaces, with regard for equity, and a desire to know: *What does an elephant look like?*

### Ethics at Toronto Rehab



#### *Congratulations and a farewell!*

Bioethicist Rochelle Maurice (pictured above) left Toronto Rehab on May 1st to accept the position of Assistant Professor in the School of Social Work at McMaster University. This is a teaching-track position focused on undergraduate and graduate education and field education and will give her the opportunity to share her expertise and experience with a fortunate new generation of Social Work students. We will miss Rochelle’s warmth and her calm presence, but we are very excited for her, and will continue to collaborate with her on matters related to the ethics of the professions. A search will begin soon for a part-time ethicist to join Ruby Rajendra Shanker (pictured below) who continues to support all of the Toronto Rehab sites (with backup from the rest of the UHN Clinical and Organizational Ethics team). Ruby can be reached at [Ruby.Shanker@uhn.ca](mailto:Ruby.Shanker@uhn.ca).





## Transplant Ethics Rounds

Co-hosted with Ajmera Transplant Centre

June 12th, 8:00-9:00am (via Zoom)

Alberto Molina-Pérez, PhD, Universidad de Granada

### Lessons from Spain about Organ Donation Systems and Public Trust

The talk can be viewed at <https://utoronto.zoom.us/j/81598552396>

## Clinical & Organizational Ethics

Bioethicists help patients, families and health-care professionals deal with difficult ethical issues in patient care. Bioethicists have special training in ethics, moral philosophy, and conflict resolution, providing confidential consultation and mediation. Bioethicists can assist with clinical, organizational, and research ethics conflicts, and provide ethics education. Our goal is to assist individuals and groups in solving complex ethical problems so they can make the right decision at the right time for the right reasons.

## Reflecting on Organ and Tissue Donation

National Organ and Tissue Donation Awareness Week, April 21-27, is a good time to reflect upon the significance of organ donation. UHN has a dedicated transplant ethicist, Jed Gross, who provides advice and support to any of those who are navigating the ethical complexities associated with this ever-evolving area of practice.

Approximately 3,000 patients receive solid organ transplants annually in Canada, however, another 3,000 people remain on the waitlist for deceased donor organs at any given time. A single deceased donor may save up to eight lives, and the gift of organ donation is one way that patients and those who love them can find meaning at life's end.

Ontario is an *opt-in* jurisdiction, meaning that organs and tissue will not be retrieved for transplant or research unless the donor or their authorized decision-maker (typically a family member, although it need not be) has given authorization. Whether organs are useable for transplant, and how many are usable, depends on circumstances at the time of death. It's wise not to make assumptions about whether a person's organs and tissue might be suitable for transplant; this is a matter best left to the judgment of clinical experts. There have been organ donors over the age of 90, and one Canadian tissue donor was over 100.

Registration at [beadonor.ca](http://beadonor.ca) or at a Service Ontario location may seem straightforward, but some aspects merit attention. There is a form that allows individuals to choose donation for transplant only or for transplant-related research. The form also allows donors to specify organs or types of tissue (e.g., bone) that they do *not* wish to donate. Those renewing a driver's license, and wanting more information, can ask to review the full form. It is important to follow the directions carefully. Checking the box indicating a wish to donate, and then checking off all the organ and tissue types in the section listing exceptions, will be interpreted as evidence that the individual did *not* wish to donate any of them. This part of the form operates as an *opt-out*, not an *opt-in*. Also, thinking about who is likely to be a legally authorized decision-maker at life's end is important. Organ donation is theoretically based on the wishes of the deceased, but in practice great deference is paid to the preferences of loved ones at the bedside. For this reason, those with strong feelings about donation should communicate their views to those closest to them. Transplant medicine raises some tough ethical issues (more to come in future editions of the newsletter), but these steps can help honour the donor's values and wishes, something that we are all aiming to achieve.

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