



# The Invisible Compass

## The Role of Spirituality in Ethical Decision-Making

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We are privileged to provide care on lands that Indigenous peoples have called home for thousands of years.



# Webinar Housekeeping

- Everyone will be muted except the host, moderator and panelists
- Ask questions through the Teams chat box
- All webinars will be recorded and posted on the internal PEaCE Hub page and on the Regional Ethics Network Website
- Please take a moment to scan the QR code to complete the evaluation
- Next month's speaker

HHS Ethics Rounds & Community  
Education Sessions



## *Disclosure*

The presenters have no conflicts of interest to disclose.

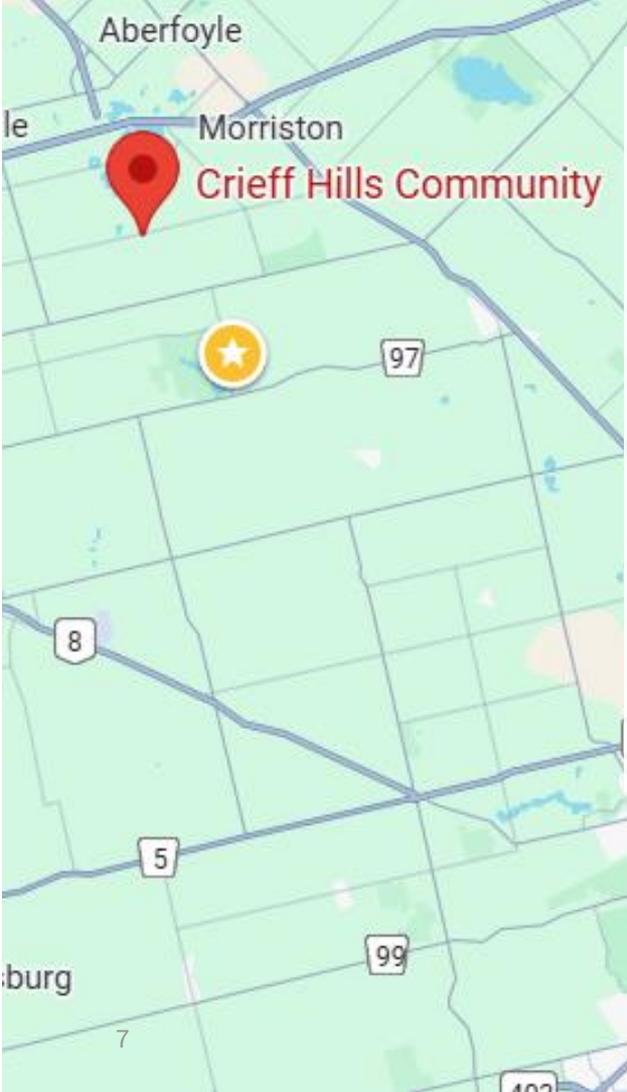




**OBJECTIVES:** Attendees will:

- *Understand how spiritual care assessment and intervention can be a determinant in patient/family ethical decision-making.*
- *Be able to define spiritual and existential distress.*
- *Understand the scope of practice for Spiritual Care in hospital settings.*



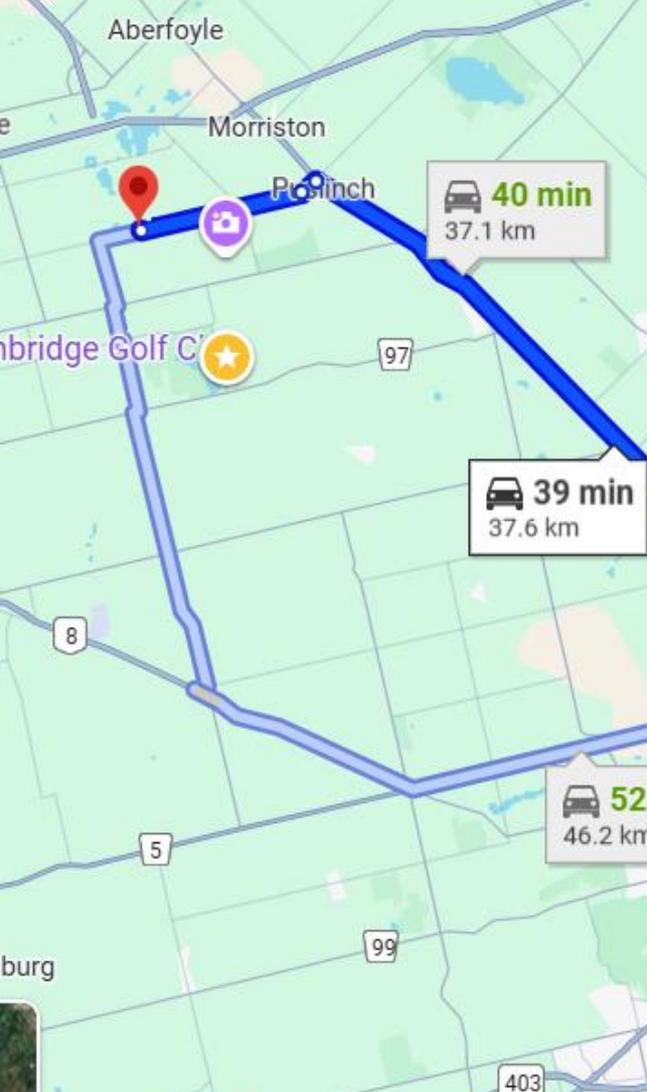


"Spirituality is the aspect of humanity that refers to the way individuals seek and express **meaning and purpose** and the way they experience their **connectedness** to the moment, to self, to others, to nature, and to the significant or sacred."

Christina Puchalski, MD, Director of the George Washington Institute for Spirituality and Health

- ▶ What do you most **value**?
- ▶ What is your main source of meaning/purpose?





Spirituality is a relationship to what we ultimately value, and a commitment to live in a way consistent with what our values demand.

This is often mediated by **sacred experiences.**

How do you CONNECT to your sense of purpose?





## Disconnection

Something - illness or climate change or violence threatens to dislodge us from the peace and safety we innately yearn for. This generates great anxiety and fear, and can lead to despair or disengagement from the reality of our lives.

**What disconnects you from what is most important?**





## **Existential Distress**

The word “existential” refers to our existing in the world. Existential distress refers to threats to our way of existing.

## **Spiritual Distress**

Spiritual distress brings the added nuance of the sacred dimension of life. People may lose connection with their sources of love, peace, and identity.







A Spiritual Care Practitioner supports a patient, family member or staff member in a way that makes an inward, existential shift possible. The encounter fosters a sense of peace, an openness to mystery, an avenue for authentic self-sharing, an opportunity for emotional expression, a field for new insight, a hospitable space to seek and engage the sacred dimension flowing beneath the surface of things.

Situations of tragedy or celebration, death or birth, suffering or relief, despair or cure – all are portals to perception of life’s generous yes to being. These existential shifts can be profoundly restorative, and by embedding spiritual care practitioners in healthcare settings, the system provides midwifery for the sacred to be born in any circumstance.





## Spirituality and Ethics

What is the role of spirituality and spiritual care in ethical decision-making?

We will explore this question through a case example.

“Spirituality is the wellspring of ethics. Ethics without spirituality is rootless; spirituality without ethics is disembodied.”

Richard M. Gula, Spirituality and Ethics in Healthcare, *Health Progress*, July-August 2000



## Spirituality and Ethics

This case centres on infant loss in a Neo-Natal Intensive Care Unit (NICU). We acknowledge the very sensitive nature of such a loss and offer respect and care to attendees at this webinar. If the case story evokes distress for you please do whatever you need to care for yourself, and reach out for support as needed.



## Spirituality and Ethics

For the sake of narrative integrity I will say:

- This is my perspective on a many-layered case, intended to clarify the role of spiritual care.
- The case overview is a bit like watching a movie based on a book. When you read the book later, much of the nuance, detail and complexity can be told, from many different points of view.
- While the presentation zooms in on the spiritual care role, the positive process outcome resulted from many care modalities coming together in a good way.



## Spirituality and Ethics

### Case

A healthy full term baby was injured during delivery at a distant hospital. Upon arrival in NICU, the baby was assessed to have a serious brain injury and the prognosis was poor, anticipating the child would have severe cognitive deficits and no chance of survival without life-long interventions for breathing and feeding.



## Spirituality and Ethics

Parents (Alex and Ry) each had children from a previous relationships, and this baby was their first child together. Parents were candid about their addiction and mental health. Parents had become sober in recent years and expressed hope they could get through this crisis without relapsing.



## Spirituality and Ethics

Psycho-Spiritual Care became involved shortly after arrival in NICU. Parents were not religiously affiliated, but cherished a personal faith and had found spirituality to be integral to their addiction recovery and healing journey. Spiritual care provided supportive conversation and prayer/blessing at bedside, and a rapport of trust quickly developed.



## Spirituality and Ethics

In view of the baby's condition, from the position of the medical team, it seemed that palliative and end-of-life care would be the logical goal and standard of care. However, the parents believed another practitioner's NICU medical assessment gave a more positive prognosis and suggested they could be facing life with a child with disability.

Parents latched on to this hope and considered new goals of care to prolong life and stabilize the child.



## Spirituality and Ethics

The parents began to question the treatment approach and advocate for external medical opinions. Conflict arose. They refused to consider a palliative journey and face this tragic loss but purposed to “fight for our child”. “You are giving up on the baby, but we never will.”



## Spirituality and Ethics

Length of stay extended to several weeks. The baby required full ventilation and feeding to sustain life. Staff expressed moral distress, since every medical indication about the baby's medical situation suggested palliative and end-of-life care was in the team's medical and professional opinion, the medically appropriate and compassionate option. Staff expressed distress and anger at what they perceived as futile life extension and possible needless harm to the child.



## Spirituality and Ethics

Over time, parents gravitated to different views. Alex said, “I know in my heart my baby is dying.” Ry said, “we won’t give up”. Ry, who did not want to give up, became argumentative with the team to the point that security was called in to establish a respectful behavior contract as a condition of Ry continuing to visit in hospital.

At this stage, spiritual care involvement evolved to focus on the parents’ emotional well-being. The trusting rapport developed at bedside was basis for a de-escalating, grounding effect for Ry.



## Spirituality and Ethics

### One key moment:

During a goals of care conference with the inter-professional team, Ry left angrily. Spiritual care left the meeting with Ry to support. In the sunlit hallway, I placed a hand on Ry's shoulder and said, "I know what you are doing is motivated by love." Ry's demeanor changed and they openly wept. The moment helped them, even briefly, to step away from angry entrenchment and connect with their deep sadness.



## Spirituality and Ethics

What values did Ry hold?

Share your thoughts in the chat.



## Spirituality and Ethics

Over the next two weeks the goals of care conflict was unresolved. Ry's temper flared. The team was frustrated. Consulting with the physician and clinical manager, spiritual care liaised with Ethics to request a consultation.

Ethics met with the team, then with team and family. Palliative care team was present in tandem with NICU team members.



## Spirituality and Ethics

Ethical decision making is hinged on values, morals and beliefs.

The ethics consultation was incredibly effective.

- The neutral and compassionate facilitation made space for sharing of information and elucidation of values. The argumentative dynamic that had developed was disarmed by the conversational space that combined clarity of ideas with emotional sensitivity.
- New goals of care for palliation resulted. Several days later supports were withdrawn and a meaningful end-of- life journey was tended.



## Spirituality and Ethics

What did spiritual care contribute?

- Initial **trust-building** at the crisis point of NICU admission allowed opportunity to care for the story.
- The rapport of trust **enabled** parents to work through their beliefs and values.



## Spirituality and Ethics

What did spiritual care contribute?

- **Care for the story** included the sacred dimension of parents' life journey. Through addiction recovery, therapy and spirituality, they had begun a new journey. Face with devastating tragedy, they were glad for prayer, blessing and assurance that their spiritual values were integral to their journey through crisis and loss.

In crisis, parents understandably lost connection to their spiritual selves – lost the invisible compass of intuition, faith and trust that could guide them through tragedy. Spiritual care did not provide guidance. Spiritual care helped them find their inner compass.



## Spirituality and Ethics

### **Reframing their understanding of their story.**

#### Family held beliefs:

- The child is loved by the Divine.
- The child's life story would continue beyond death.
- The child's essence would continue to be with them.
- In the face of tragedy, one is called to respond in a principled and emotionally authentic way.
- "I love my child".
- A terrible injustice occurred when the baby was injured.
- No one should go through something like this.



## Spirituality and Ethics

### Reframing

The care team assisted the family to re-narrate the story.

Their value of love for the baby found new expression. Not the journey they envisioned, but a journey that could still be shaped by courage, togetherness and hope.

The “Higher Power” that was caringly present at other times of life struggle continued to be present as a guiding compass.



## Spirituality and Ethics

### What is the role of Spiritual Care in Ethics?

Spiritual care assists people to navigate distressing and morally complex circumstances with greater access to the sacred dimension of their lives.

As this connection to the sacred deepens, spiritual care assists people to identify values, participate in ritual / ceremony, connect with their deeper self, express emotions, explore beliefs and communicate with the care team from a space of authenticity.



Discussion