

# Improving the Family Experience in Organ Donation

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# Objectives

- Introduce tools for communication throughout the continuum of care
- Discuss key elements necessary when working with hospital staff and administration
- Understand important ethical distinctions that arise in care of the family in organ donation
- Apply the tools and ethical principles to two cases involving care of the family
- As small groups, discuss common barriers to improving the family experience

breakout into small groups @ 30 min



# Reminder regarding Cases

- Cases are based on actual clinical experiences and personal details have been changed.
- Please respect the privacy and confidentiality of the actual patients and families behind these de-identified cases.
- The cases presented may not include all the information you may want in order to make your recommendation.

Nothing to disclose

When it's personal, all bets are off



Sam Caplet "Don't Let Go"

# Defining Scope

This session is intended to address the communication needs of patients and families imminently facing the natural end of their life

- Determination of death by neurologic criteria
- Death after cardiopulmonary cessation
  - Palliative Extubation
  - DCDD

# Clinical Care Common Terms: Limitations of Professional Practices

<b>IN THE PRACTICE ITSELF</b>	<b>IN THE CONTEXT OF THE PRACTICE</b>
<p><b>TERMINAL ILLNESS:</b> A serious medical condition for which no cure is available or for which treatments have failed the patient. The patient is more likely to die from this condition than from some other cause</p>	<p><b>NON-MANAGEABLE CONDITION:</b> A serious medical condition in which the treatment can no longer improve or maintain a person's functional ability or an acceptable quality of life; patient cannot pursue life goals</p>
<p><b>MEDICALLY NON-BENEFICIAL INTERVENTION:</b> An intervention that cannot produce a sustained clinical effect that is beneficial to the patient medically</p>	<p><b>CLINICALLY NON-FEASIBLE INTERVENTION:</b> An intervention or plan of care that is not possible to perform or complete due to circumstances beyond the control of the medical system or community</p>

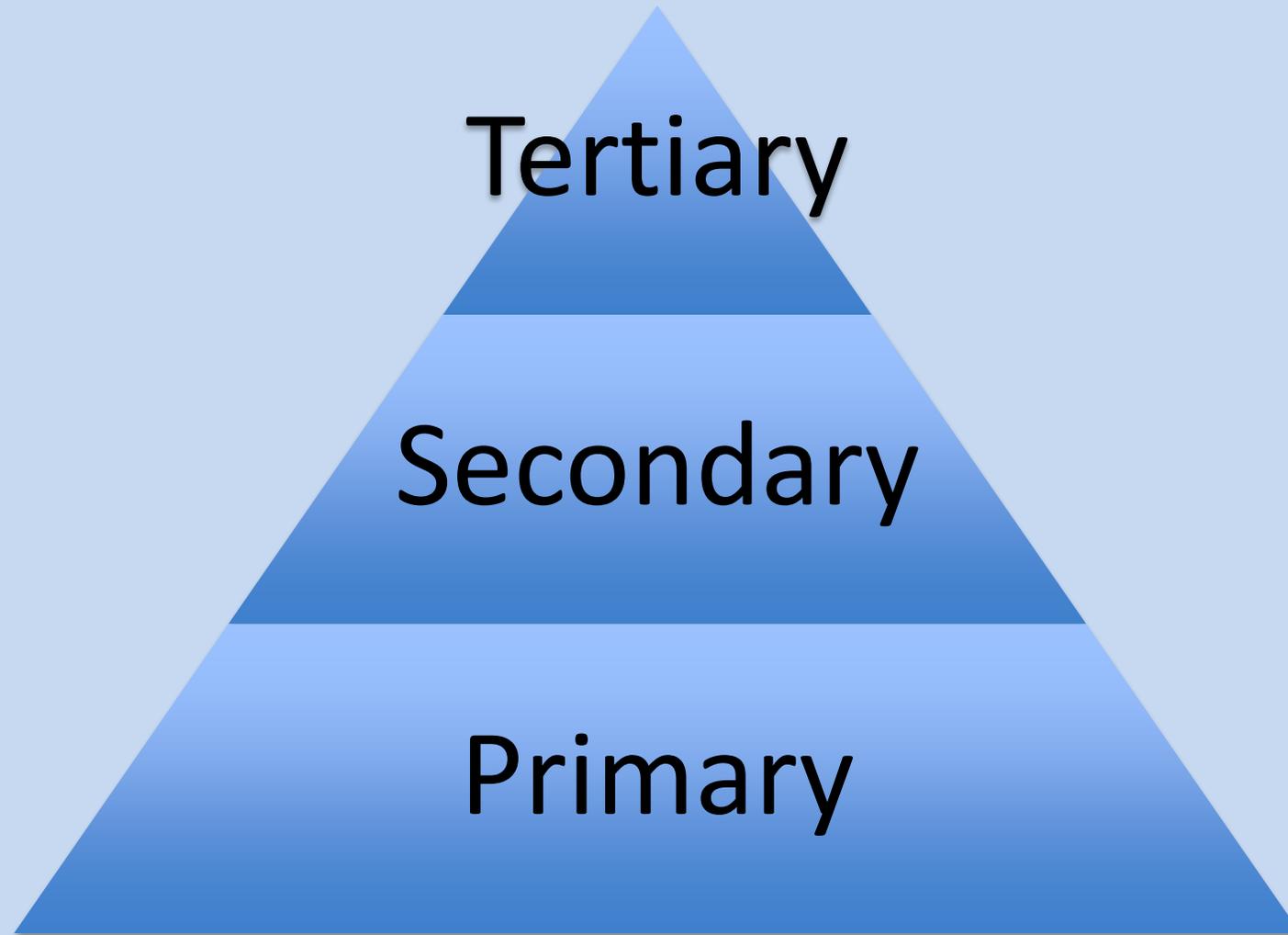
- Duty to protect life or prevent death is NOT absolute
  - Withholding vs. Withdrawing
  - Killing vs. Allowing Natural Death

# Goals of Clinical Medicine

- Promotion of health and prevention of disease
- Maintenance or improvement of quality of life through relief of symptoms, pain, and suffering
- Cure of disease
- *Prevention of untimely death*
- Improvement of functional status or maintenance of compromised status
- Education and counseling of patients regarding their *condition and prognosis*
- Avoidance of harm to the patient in the course of care
- *Contributing to a good death*

-Jonsen, et al. *Clinical Ethics*

# What is Palliative Care?



# You're sick. It's serious.



<https://www.youtube.com/watch?v=yCeZ4bGLd8g>

- “Suffering can be defined as the state of severe distress associated with events that threaten the intactness of the person. It continues until the threat has passed or until the integrity of the person can be restored in some manner.”

*- Eric Cassel, “The Nature of Suffering and the Goals of Medicine”*

# Eight Domains of Quality Palliative Care

1. Structure & process of care
2. Physical
3. Psychological & Psychiatric
4. Social
5. Spiritual, Religious & Existential
6. Cultural
7. Care of the imminently dying patient
8. Ethical & Legal aspects of care

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Little more than a decade ago intensive care and palliative care were thought to be mutually exclusive; they were seen as sequential approaches to critical illness. Today we recognize that from the time of admission to the ICU, all critically ill patients and their families should benefit from palliative care. Palliative care should therefore be provided concurrently with intensive care therapies.

# Case #1

- 42 yo gentleman with anoxic injury after sudden cardiac arrest
- Underwent therapeutic hypothermia protocol
- No improvement in neurologic status 48 hours after normothermic
- Intractable myoclonus

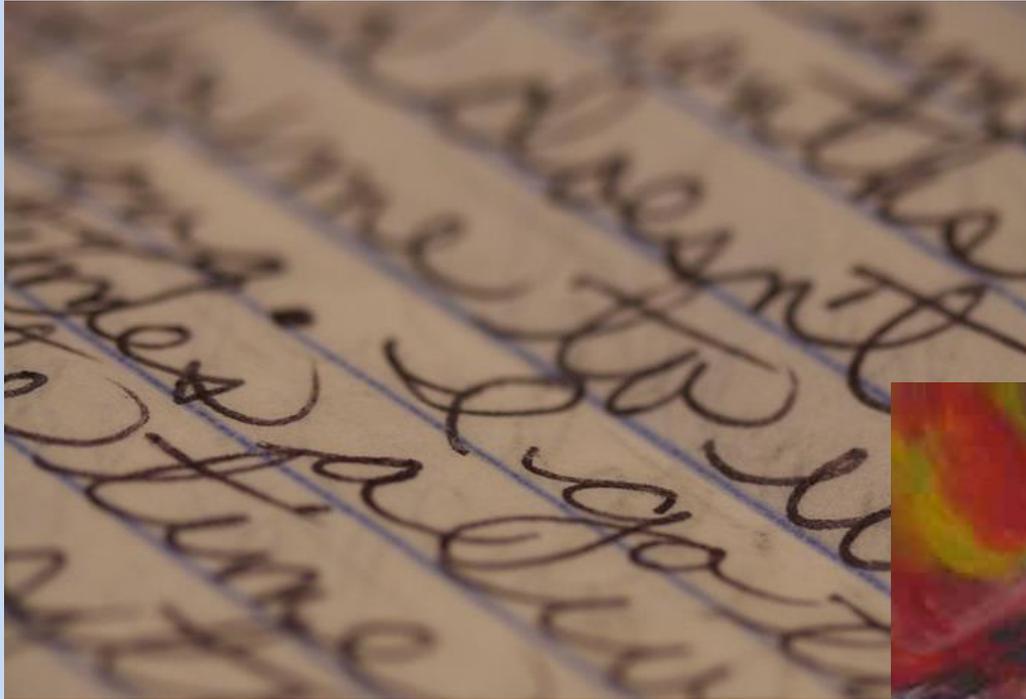
# Case #1

- Family discusses palliative extubation
- Patient was first person authorized donor
- Communicated and set expectations regarding DCDD process
- Discussed extubation procedure with family

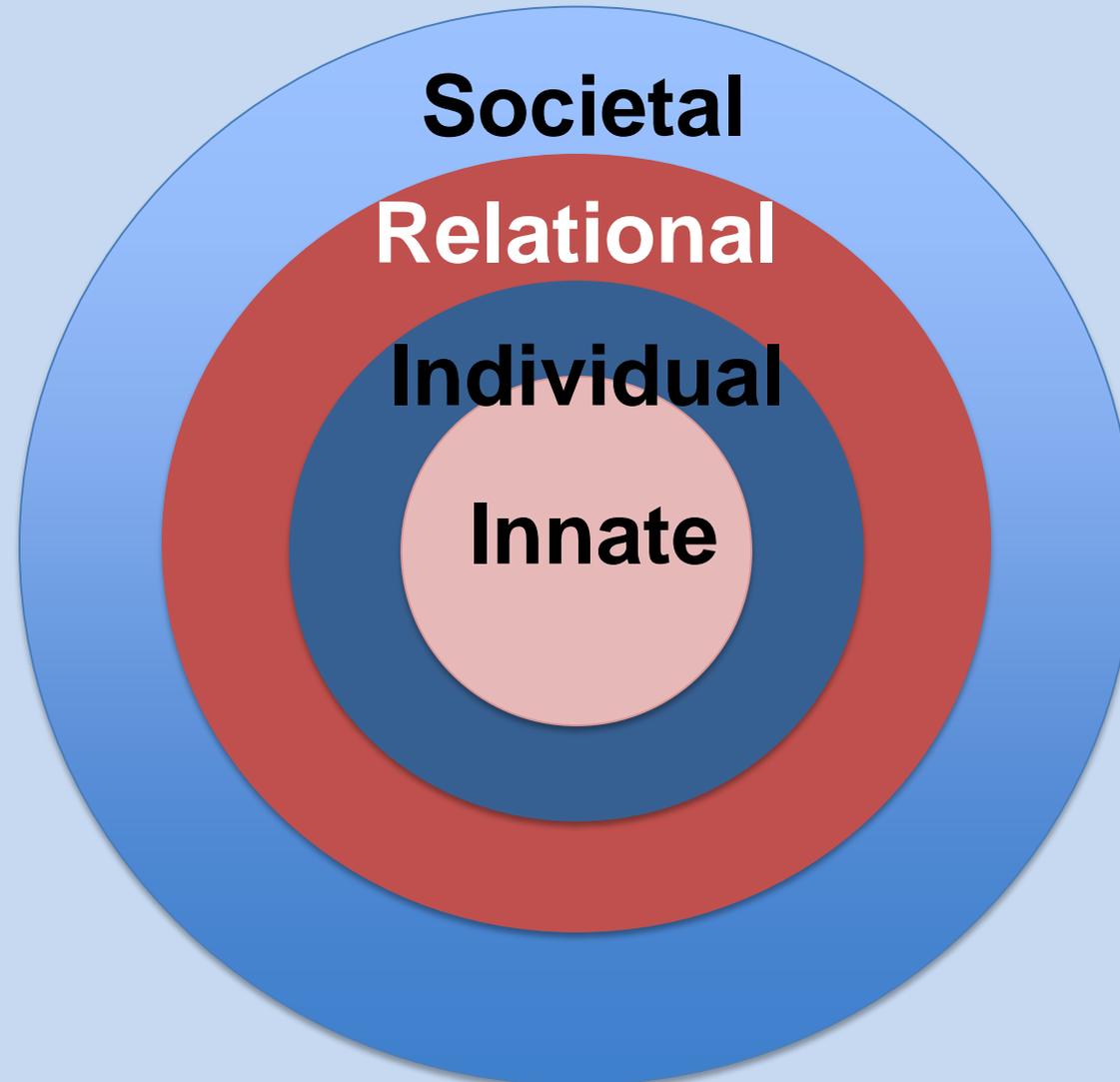
# Case #1

- Palliative Care Team consult for Palliative Extubation
- Checklist for extubation procedure and symptom management used
- Palliative care physician, RN, Chaplain, OPO representatives at bedside

# Legacy Work



# Ring Theory of Personhood



# Barriers to Supporting Bereaved Family Members

- Not knowing what to say
- Not sure how to deal with emotion
- Lack of knowledge about community resource
- High clinical workload
- Lack of continuity or established relationship with the patient or family member

# Loss related Risks for Complex Grief

- Relationship and caretaking roles
  - Spouses
  - Mothers of dependent children
  - Caretakers for chronically ill
- Nature of the death itself
  - Violent, sudden, prolonged, suicide
- Mortality in Intensive Care Unit
  - 34 to 67% of surviving family members have CG

# Other Risk Factors

- Social circumstances
- Resources available after death
- **Unknown:** Lack of information/understanding of the circumstances of the death event
- Interference with natural healing process:
  - Inability to follow usual cultural mourning
  - **Alcohol or substance abuse**
  - **Lack of social support**

## Moral Distress

Right course of action  
is known  
Unable to complete  
due to  
Institutionalized  
obstacles

## Moral Uncertainty

Unease  
Questioning  
Unclear right course of  
action

## Moral Dilemma

Multiple conflicting  
but morally justifiable  
courses of action  
Unclear course of  
action

← DISCOMFORT →

## Case #2

- 28 yo woman with GSW to head
- GCS 3, Initially with intractable seizure despite ativan/valium
- Phenobarbital used to control seizure
- Brain death suspected, awaited clearance of phenobarb

## Case #2

- Family brought up donation while awaiting phenobarb clearance
- Brain death suspected after mutually agreed upon waiting time
- Brain death declared clinically, Nuclear Brain Scan\* ordered as adjunct determining irreversibility

## Case #2

- In the process of finding donor organ recipients, patient had cough reflex
- Brain death examination repeated, no longer consistent with brain death- time of death recanted.
- Family devastated

# VALUE Mnemonic

- V = Value family statements
- A = Acknowledge emotion
- L = Listen to the family
- U = Understand the patient as a person
- E = Elicit family questions

# Tool Belt



“Ironworker’s Tools” National Museum of American History, Smithsonian

# Communication Tool Belt

- Physical tools - self and environment
- Emotional tools
- Cognitive tools
- Orchestrating tools

# Physical Tools

- Using self and environment to aid communication
  - Location
  - Body language
  - Arrangement
  - Mirroring
  - Appearance
  - Attendees

# Emotional Tools

- Interacting with emotion to aid communication
  - Active Listening – requires empathy
    - Therapeutic presence
    - Echoing “so I hear you saying”
  - Naming
  - Validating
  - Normalizing
  - Silence
  - Rationalize
  - De-escalation
  - Self monitoring

# Cognitive Tools: Part 1

- Identify barriers
  - Knowledge deficit
  - Language barrier
  - Cultural barrier
  - Learning disability
  - Psychosocial barrier
  - Hearing disability
  - Visual disability
- Teaching Methods
  - Interpretation of medical language
  - Visual aids
  - Analogy/metaphor
  - Gestures
  - Reframing

# Cognitive Tools: Part 2

- Check for understanding, clarify
  - Summarize
  - “Take one for the team” clarification
  - Request questions
  - Request a teach-back

# Orchestrating Tools

- Mode
  - Verbal vs. written
  - Open vs. closed questions
  - “painting a picture” with body movement
- Approach
  - Paternalism (“owning” plan of care)
  - Aligning (allying, partnering)
  - Permissive (accommodating, avoiding)
  - Neutral (Impartial)

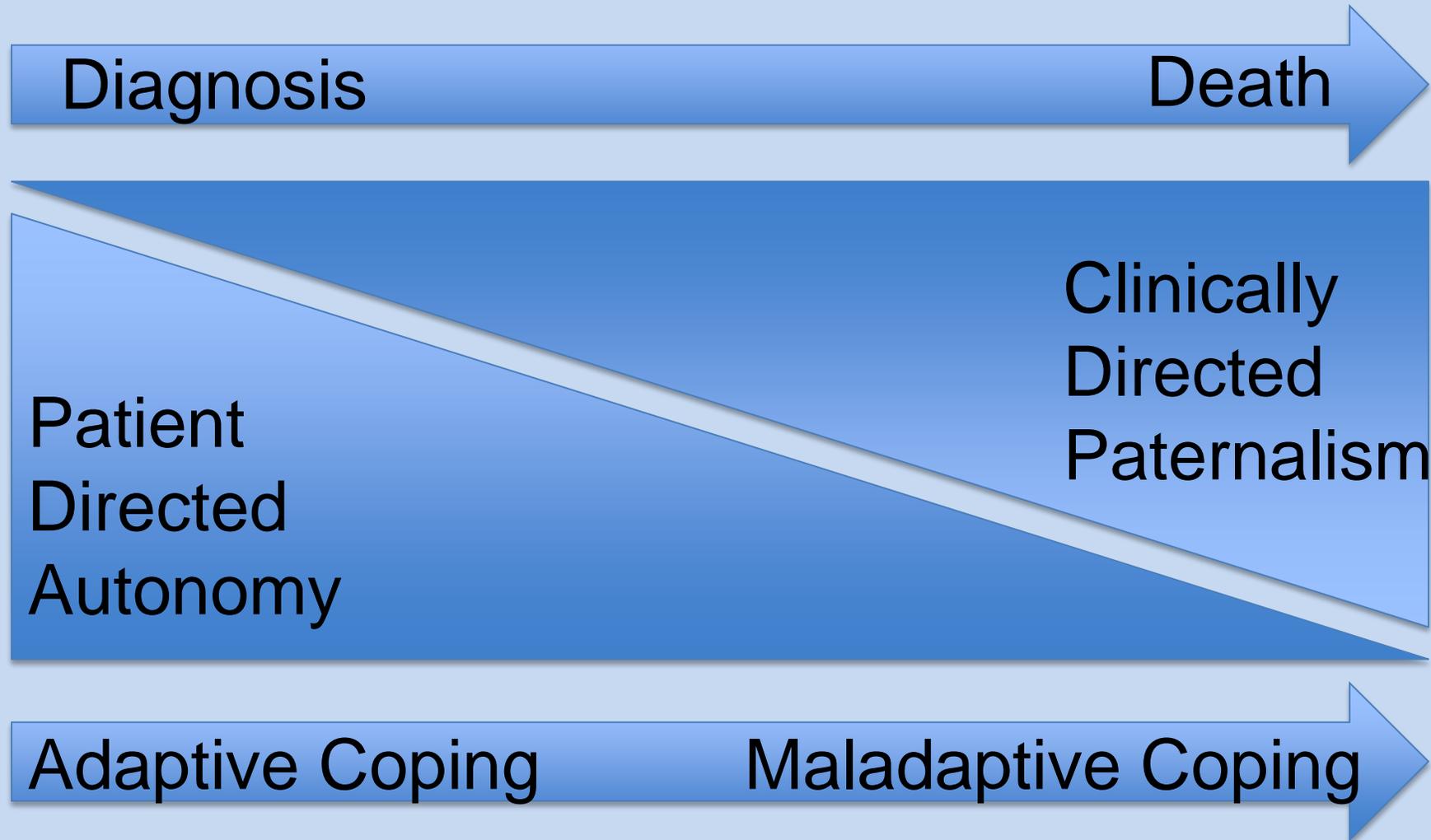
# Orchestrating Tools

- Delivery
  - Titration of information (simple vs. detailed)
  - Organization/Prioritizing
  - Tempo
    - Rate
    - Rhythm
    - Pauses
    - Interrupting
    - Redirecting
  - Manner:
    - soft, gentle vs. direct, blunt

# Code Status: Language Matters



# Spectrum of Shared Decision Making



# Autonomy & Reciprocity

- Does the patient/family understand what's wrong?
- What do they think is a good outcome?
- What is my patient's cultural, religious, or ethnic point of view?
- Who does the patient trust to make decisions for them if they lack capacity?
- What are my patient's goals and aspirations?
- What/Who are my patient's support system?

# Cultivating therapeutic presence in midst of conflict



What are the barriers you encounter in caring for patients and families during the donation process?

Break out into discussion groups of 4-6 people around you

# Who decides?

- Surrogate decision making
- What about the “unbefriended/unrepresented” patient?
- When ought a guardian be appointed?
- Medical Paternalism v. Autonomy in unilateral decisions

# Substituted Interests

- When the patient's wishes are *unknown*
- Combines universal principles with patient's known values & interests
- Requires empathy, connection and trust

# Self Care

When you do the physically and emotionally hard work of caregiving and bearing witness to suffering.

You must cultivate tools to  
nourish your soul.

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