# When Hope is a Heavy Burden: Working with Futility in End of Life Care

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## Objectives

- Apply the family systems illness model to 'terminal' stage care with veterinary families
- Explore what medical futility means in the context of core bioethical issues
- Review 'edge states' in practitioners and reframe the role of compassion in working with death and dying
- Propose tools for navigating difficult end of life situations with veterinary patients and clients

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## Case Study: *Blaze*

- 10 y.o. Shih Tzu dx multiple myeloma in 2014
- Presented to ER with anemia, blood-tinged urine and paraparetic; out of remission
- Client referred for hemodialysis and chemotherapy, neither of which was recommended
- Full CPR orders
- Client unwilling to shift to DNR; acquiesced to DVM refusal to dialyze
- 2.5 days ICU, arrested and unable to be resuscitated

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## In Context:

- Patient sole source of biopsychosocial support for client
- Client divorced, estranged from adult children, living alone
- Client was sole caregiver for father, who died of undisclosed disease after prolonged hospitalization; client refused to remove life support
- Client a person of faith

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## Family Systems Illness Model (Rolland, 1984)

- We cannot understand client behavior/choices apart from the system that creates, maintains, and constrains behavior/choices
- The job of the veterinary team is twofold: to build a functional relationship with the entire system, and to prepare the system ***to care-give and to let go.***

***Key:*** Patient vs. Family as ***unit of care***

## Illness – and Caregiving -- in Context

- Family caregivers often working with insufficient resources, support and training (Zuckerman & Wollner, 1999)
- Only 12% of adults in the U.S. have proficient "health literacy" (NCES, 2006)
- Family proxies often make over/under-treatment errors based on status of patient and "projection bias" (Allen et al., 2006)

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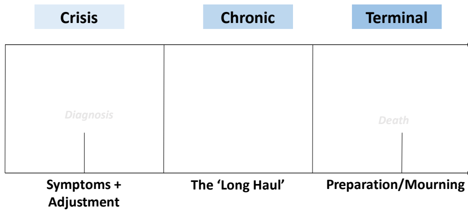
## Family Needs are Determined by Phase of Illness




## Families in the Terminal Phase of Illness

***Clients need:***

- To relinquish hope
- To prepare for death emotionally/practically
- To honor spiritual/cultural beliefs about death/dying
- To "circle the wagons"

***The Veterinary Team needs:***

- To *'start where the client is'*
- Direct, compassionate communication
- To know "no-go zones"
- To refer for outside services, when necessary
- Closure with the client system

(Rolland, 1994)



## Good Deaths are Collaboratively Constructed

***Clients Need:***

- To honor spiritual/cultural beliefs around death and dying
- To have choices about participation
- To have structure around an uncontrollable process
- To have few surprises around how death unfolds (Steinhauser, et al., 2000)

***The Veterinary Team Needs:***

- *To be an "exquisite witness"* (Jeffreys, 2005)
- To plan ahead for complications
- To provide a calm and safe environment (Lagoni, et al., 1994)
- To be flexible, patient, and calm

## Futile Care: What is "Hopeless?"

- Indicates physiologic impossibility of intended treatment achieving target therapeutic objective and assumes a value-neutral stance(Post & Blustein, 2015)
- Often confused with *ethicality* (inappropriate vs. non-beneficial tx)
- Bioethics now considers futility to be ***consensus-based***

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## The Realities of Medical Futility in Practice

- Lack of *understanding*, *time*, and *exposure* contribute to futile care requests
- Even when requested treatment is "not clinically indicated, " there is always something left to offer/provide (including palliation)
- Medical protocols negotiate and *ritualize* the process of death (Mohammed & Peter, 2009)

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## Four Triggers for Conversations about Ethics and Futility

1. Moral imperative to relieve pain
2. Moral imperative to relieve suffering
3. Forgoing life sustaining tx (support of organ systems) to *allow* death
4. Euthanasia to *facilitate* death; agent of death is the clinician with *consent* of client

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## The Role of Ethics Consultation/Mediation

- Structured method of helping medical teams, medical patients, and other involved parties resolve concerns
- Common in human hospitals – and *required* in some states
- Reduces lengths of stay, provision of non-beneficial care, and turnover of medical staff; may reduce moral stress/distress in professional caregivers
- Goal is to promote sound biomedical decision-making that balances concerns and achieves the "least worst" outcome for the patient

(Post & Bluestein, 2015)

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## Remember the ABCDs of Dignity Conserving Care

A. Attitudes/assumptions affect practice
B. Behaviors should always enhance patient/client dignity
C. Compassion requires sensitivity to suffering
D. Dialogue is critical to acknowledging selfhood/strengths beyond illness

(Chochinov, 2007; Cook & Rocker, 2014)

## Tool #1: Provide Emotional & Instrumental Support

- Normalize and validate
- Prescribe movement, glucose, rest & hydration
- Writing, repetition, and reflection may improve processing
- "Circle the wagons" to ensure psychosocial resources are provided

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## Tool #2: Examine Shared Values & Goals

- Common ground is critical to navigating difficult situations
- Clarify values, interests, and concerns to identify barriers to sound decision-making (Back et al, 2005; Shannon et al, 2011)
- Incremental points of agreement can be used to build solutions/consensus (Dubler & Liebman, 2004)

**What is your understanding of ________'s condition?**

**If ____'s condition gets worse, what are your goals? Fears?**

**What is acceptable for you to gain more time together? Would this change if he/she doesn't improve?**

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## Tool #3: Reframe

- ***Shift focus*** to quality, not quantity
- At some point, aggressive curative intent is counterproductive in terms of comfort, time spent with family, and capacity for enjoyment
- Giving up vs. ***giving permission*** (sense of loss and defeat with cessation of curative intent care)

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## Tool #4: Attend to Cognitive Dissonance

- Calling attention to a strongly held value, then giving an example of how current behavior/choice violates that value or is incongruent, can generate more congruent problem-solving (Rooney, 1992).
- Those who are presented with more than one side of the issue may be more likely to be persuaded (presenting "for" and "against" withdrawal of curative intent tx) (Rooney, 1992)
- If insight or understanding are limited, encourage taking the role of the patient to generate empathy (Rooney, 1992)
- *Best used with caution and when behavior/decisions are potentially dangerous to client/patient*

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## Battle Fatigue: Awareness is Key to Self Management

Common roles of wounded healers (Halifax, 2009):

- **The Hero** (the rescuer) – "nobody can do it but me"
- **The Martyr** – knee-jerk compassion despite exhaustion and resentment
- **The Parent** – patronizing, micromanaging, treating client (or other staff) like incompetent
- **The Expert** – emotional distancing to cope with uncertainty and discomfort
- **The Priest** – preaching the right path and the 'best way to die'

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## Beware the Five "Edge States" of Pathological Altruism (Halifax, 2011)

1. Burnout (vital exhaustion)
2. Secondary trauma (empathic overarousal)
3. Moral distress (not being able to actualize what we are called to do)
4. Horizontal/vertical violence (displaced aggression)
5. Structural violence (organizational policy that harms instead of heals)

*… all of which impact the healer, the client, and the patient*

## In the Moment: Healing the "Empathy Rift"

- *Breathe* and embody equanimity
- Ask for consultation and support
- Check your stories and suspend judgment
- Remember that even suffering is impermanent
- When necessary, practice *ethical termination and referral*

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## In the Aftermath: Healing Exhaustion, Frustration, and Moral Stress

- Cultivate alignment with your sense of service and purpose
- Find, and use, your "off switch" (unplug and reboot)
- Make time for reflection
- Tune into, and move, your body
- Cultivate gratitude

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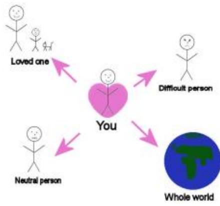
## Exercise: Metta (Compassion) Meditation




- May you be happy
- May you be well
- May you be safe
- May you be peaceful and at ease

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## Questions and Reflections?

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