

The background features a series of overlapping, semi-transparent green geometric shapes, primarily triangles and quadrilaterals, that create a sense of depth and movement. The colors range from a light, pale green to a vibrant, saturated lime green. The shapes are layered, with some appearing to be in front of others, creating a complex, layered effect. The overall composition is clean and modern, with a focus on geometric forms and color gradients.

# Healing When Cure Is Not Possible

# Definitions

- ▶ Palliative care
- ▶ Hospice care
- ▶ Advance Directive
- ▶ Do Not Resuscitate

# Goals of Care

- ▶ Eliciting parental concerns
- ▶ Obtaining developmental history
- ▶ Making accurate and informative observations
- ▶ Sharing opinions/concerns with other relevant professionals

# Decision-making Tool

- ▶ Medical indications
- ▶ Patient and family preferences
- ▶ Quality of life
- ▶ Contextual issues
- ▶ Discussion
- ▶ Plan

Medical Indications	Patient Preferences
<p>In this area, document diagnoses and symptoms:</p> <ol style="list-style-type: none"> <li>1. Potential medical interventions/options for treatment</li> <li>2. Risks/Benefits</li> <li>3. Cure rate/remission rate/length of remission</li> <li>4. Recurrence rate</li> <li>5. Complications/complication rate</li> </ol> <p>Treatments for temporary conditions unrelated to the primary diagnoses are included here.</p> <p>The discussion may be divided into curative, life extending, and/or comfort care issues.</p>	<p>In this area, document the patient's preferences/goals re:</p> <ol style="list-style-type: none"> <li>1. Being informed</li> <li>2. Being involved in decisions</li> <li>3. Desire for autonomy</li> <li>4. Desire for privacy</li> <li>5. Each specific treatment option</li> </ol> <p>If the patient is too young or unable to express preferences, the "best interest" standard is used and generally determined by the parents or legal guardians. Assent by the patient may be noted.</p>
Quality of Life	Contextual Issues
<p>The components of life that give value and meaning to the patient are noted here. Children often respond to "What do you love to do?" Note:</p> <ol style="list-style-type: none"> <li>1. Important activities</li> <li>2. Important relationships</li> <li>3. Personal identity</li> <li>4. Emotional well being</li> <li>5. Spiritual well being</li> </ol> <p>When the patient is unable to render opinions, the parents or legal guardians may offer opinions.</p>	<p>In this area, note the circumstances of the child's life:</p> <ol style="list-style-type: none"> <li>1. Who lives in the child's home</li> <li>2. Primary caregiver</li> <li>3. Extended family and friends</li> <li>4. Financial/Insurance facts</li> <li>5. Study protocols</li> <li>6. Legal issues</li> <li>7. Cultural and spiritual beliefs/needs</li> <li>8. Physical restrictions/modifications of home</li> <li>9. Family history of condition</li> <li>10. Needs/opinions of professional caregivers</li> </ol>

Discussion
Discussion regarding the information in the four boxes is noted here. Implications and priorities are enumerated in such areas as: <ul style="list-style-type: none"><li>1. • Medical care options</li><li>2. • Goals for care</li><li>3. • How the information relates from one box to the others</li></ul>
Plan
The plan of care is dynamic and is to be altered in response to patient/family request, medical indications, and decisions reached collaboratively with the care planning team. Each issue is noted separately on the Plan. Algorithm use is noted. The family receives a copy of the completed Decision-Making Tool and blank Decision-Making Tool forms.

# Symptom Management

- ▶ Pain control
- ▶ Secretions
- ▶ Anxiety/Agitation

# Which face represents what you are feeling?



**0**  
**NO**  
**HURT**



**1**  
**HURTS**  
**LITTLE**  
**BIT**



**2**  
**HURTS**  
**LITTLE**  
**MORE**



**3**  
**HURTS**  
**EVEN**  
**MORE**



**4**  
**HURTS**  
**WHOLE**  
**LOT**



**5**  
**HURTS**  
**WORST**

# Communication

- ▶ With parents
- ▶ With extended family and friends
- ▶ With law enforcement
- ▶ With other providers
- ▶ With medical examiner
- ▶ With organ donation center

# Members of the Interdisciplinary Team

- ▶ Physicians
- ▶ Nurse practitioners
- ▶ Physician assistants
- ▶ Nurses
- ▶ Dietitians
- ▶ Physical therapists
- ▶ Occupational therapists
- ▶ Speech therapists
- ▶ Psychologists
- ▶ Social workers
- ▶ School teachers
- ▶ Chaplains
- ▶ Secretaries
- ▶ Child life

# How we often operate

- ▶ Interpretation
- ▶ Judgement
- ▶ Lack of connection
- ▶ Demands
- ▶ Strategies

# A new way of being

- ▶ Observations
- ▶ Feelings
- ▶ Needs
- ▶ Requests

# Observations

- ▶ What we see or hear
- ▶ Give rise to our feelings
- ▶ Do not include judgements or interpretations or evaluations

# Feelings

frustrated alarmed  
anxious bereaved  
content awed joyful  
open loving hearted  
baffled elated strong  
surprised  
irritable hopeless lonely

# Needs



# Requests

- ▶ Are clear, positive, and concrete action
- ▶ Are specific and doable in the present
- ▶ Are NOT demands (“No” is a possible response, not to be met with contentiousness)

# Care of the Family

- ▶ Expect what is to be expected
- ▶ Anticipate and be proactive
- ▶ Recognize that there are many acceptable ways to do things

# Parents' Experience

- ▶ Evolving experience
- ▶ Central theme: Facing adversity

# Defining Adversity

- ▶ Characteristics of child's condition
- ▶ Family view of child's condition
- ▶ Living with loss
- ▶ Gaining strength
- ▶ Magnitude of impact

# Managing Adversity

- ▶ Seeking information
- ▶ Planning/preparing
- ▶ Negotiating
- ▶ Utilizing resources

# Facing Adversity

- ▶ Normalization
- ▶ Loss (chronic)

# Managing Dissonance

- ▶ Clarity of goals
- ▶ Effectiveness of communication

# Signs of Impending Death

- ▶ Change in appetite/intake
- ▶ Change in interpersonal interaction
- ▶ Change in skin color
- ▶ Change in respiratory pattern

# “Diagnostic and Prognostic” Challenges at the End of Life

- ▶ How long do they have?
- ▶ Is this the end?
- ▶ Are they suffering?
- ▶ Are they gone?

# Final Arrangements

- ▶ Patient input
- ▶ Family input
- ▶ Medical examiner
- ▶ Funeral home
- ▶ Special requests
- ▶ Funding

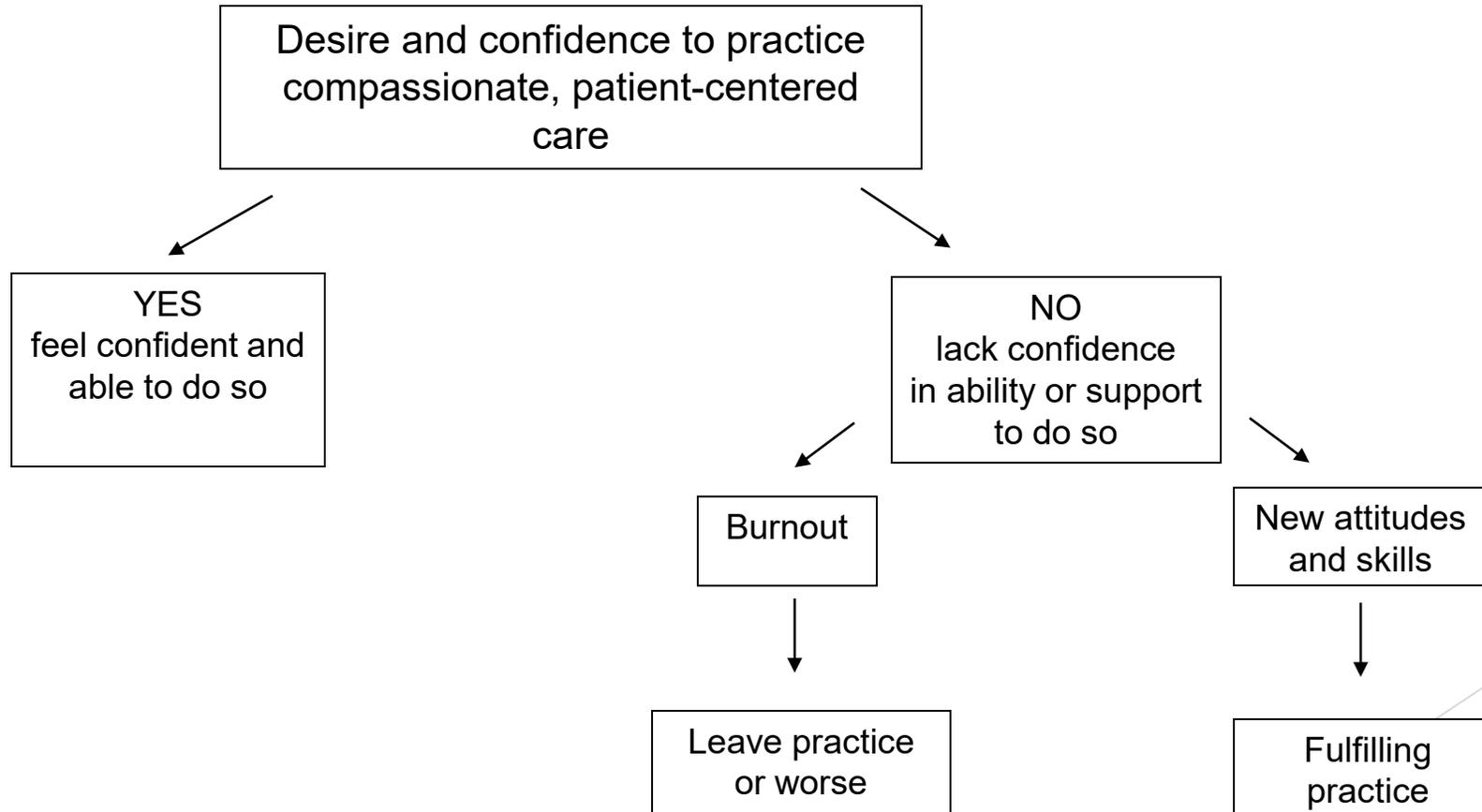
# Remembrance

- ▶ Photos
- ▶ Handprints and footprints
- ▶ Locks of hair
- ▶ Poems, prayers, quotes
- ▶ Music

# Personal Self-Care

- ▶ Preventing/reducing burnout
- ▶ Communicating and debriefing
- ▶ Recognizing meaning
- ▶ Including health-promoting, life-enhancing pursuits

# My Experience of My Practice



# Words for Reflection

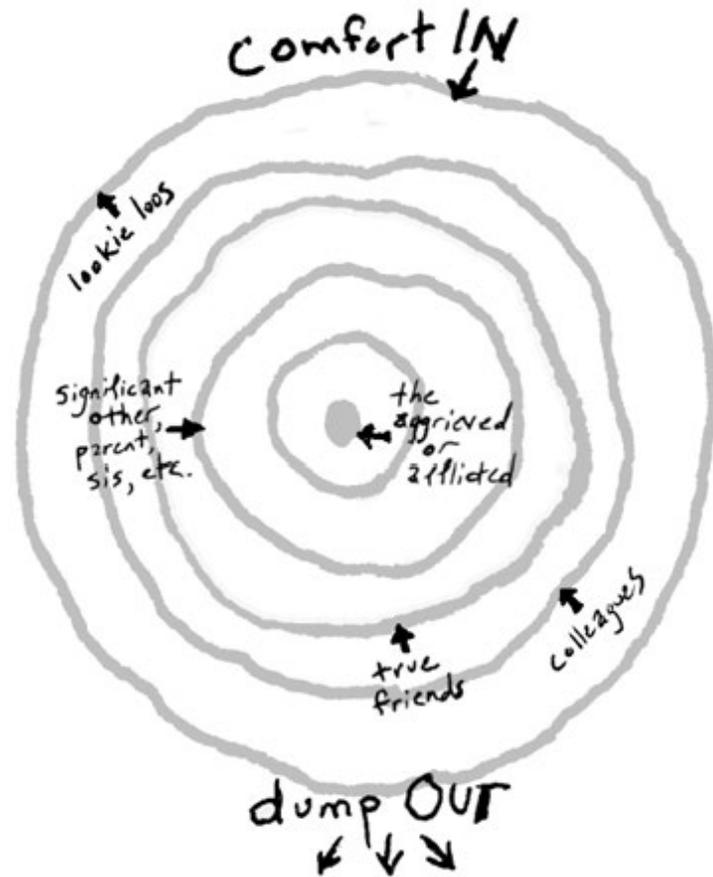
- ▶ Service
- ▶ Commitment
- ▶ Compassion
- ▶ Listening
- ▶ Suffering
- ▶ Loss
- ▶ Forgiveness

- ▶ Mistakes
- ▶ Gratitude
- ▶ Dignity
- ▶ Home
- ▶ Mystery
- ▶ Refuge
- ▶ Healing

# Healing presence

- ▶ Fiduciary relationship
- ▶ Equanimity
- ▶ Quality listening
- ▶ Empathy
  
- ▶ Less about saying or doing, but rather more about BEING WITH...

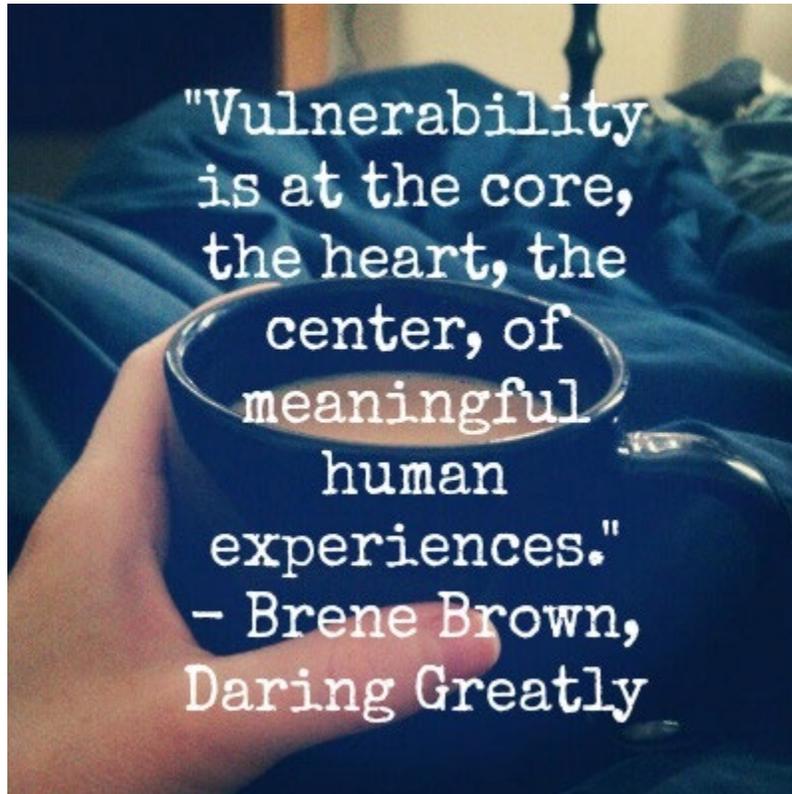
# 'Ring Theory' of Kvetching



# Spirituality

- ▶ Interview models
- ▶ Presence

# Vulnerability



# Medical Litany

*'From inability to leave well alone;  
From too much zeal for what is new and contempt for what  
is old;  
From putting knowledge before wisdom, science before art,  
cleverness before common sense;  
From treating patients as cases;  
From making the cure of a disease more grievous than its  
endurance;  
Good Lord, deliver us.'*

Sir Robert Hutchinson