EATING DISORDERS AND PALLIATIVE CARE: A NOVEL PALLIATIVE CARE CLINIC

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PROGRAM DISCLOSURE OF COMMERCIAL SUPPORT

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Agenda

- Why this matters for palliative care
- What advanced illness in eating disorders (ED) can look like.
- A patient journey
- Ethical complexity and end stage eating disorders
- Practical takeaways for palliative care providers.

Why this matters

- Rising consults for severe and long-standing eating disorders
- High symptom burden + recurrent hospitalizations
- Fragmented care across specialties
- Palliative often introduced too late -if at all
- Increasing moral distress among palliative teams

Patients who want to live — in systems struggling to support them

Why Eating Disorders & Palliative Care Intersect

Severe eating disorders can evolve into chronic, life-limiting illnesses with high symptom burden and medical risk — often over decades.

Subset of patients with **long-standing, refractory illness**

Repeated unsuccessful treatments and recurrent hospitalizations

Progressive medical complications despite ongoing care

Clinical trajectory begins to resemble other non-malignant life-limiting conditions

Symptom Burden

Patients experience multidimensional suffering that is often undertreated in traditional eating-disorder models.

Physical: refractory GI pain, dyspnea, nausea, constipation, fatigue, weakness, generalized pain

Psychological: severe anxiety, panic, insomnia, depression, cognitive impairments & increased obsessionality

Functional: loss of independence, frequent admissions, poor quality of life

Despite looking cachectic and frail, their labs are normal!

Markers of Advanced Disease

- BMI ~11–12 kg/m^2 with profound malnutrition
- Cytopenias and electrolyte abnormalities
- Hypoglycemia, arrhythmia, seizures,
- Frailty, sarcopenia and falls
- Quadriceps and pharyngeal muscle weakness

Medical Complications of Eating Disorders That Signal Medical Fragility

Table 1.

Eating Disorder Symptoms and Associated Potential Medical Complications

Symptom	Medical Complication
Restricting	Altered metabolism with hypothermia, cognitive impairment, dizziness, hypotension, bradycardia, orthostasis, amenorrhea, edema, fatigue
Bingeing	Obesity, hypertension, hyperlipidemia, insulin resistance, joint deterioration, dyspnea, sleep apnea, gallbladder disease
Vomiting	Electrolyte imbalance (hypokalemia), arrhythmias, esophagitis/gastritis, gastroesophageal reflux disease, dental caries, dehydration, alkalosis, parotid/submandibular gland hypertrophy
Laxative abuse	Cathartic colon, dehydration, electrolyte imbalance, metabolic acidosis, alkalosis
Diuretic abuse	Dehydration, electrolyte imbalance
Appetite suppressant abuse	Hypertension, tremor, arrhythmias
Ipecac abuse	Myopathy, cardiomyopathy
Water loading	Hyponatremia, headache, nausea, dizziness, seizure

High Risk Flags

Physiologic	Neuropsychiatric
Bradycardia	Delirium
Hypotension	Depression
Prolonged QTc	Suicidal ideation
Electrolyte derangements	Cognitive rigidity / impaired insight
Refeeding syndrome	Severe anxiety or panic impacting treatment

Ethical Complexity & Medical Decision-Making

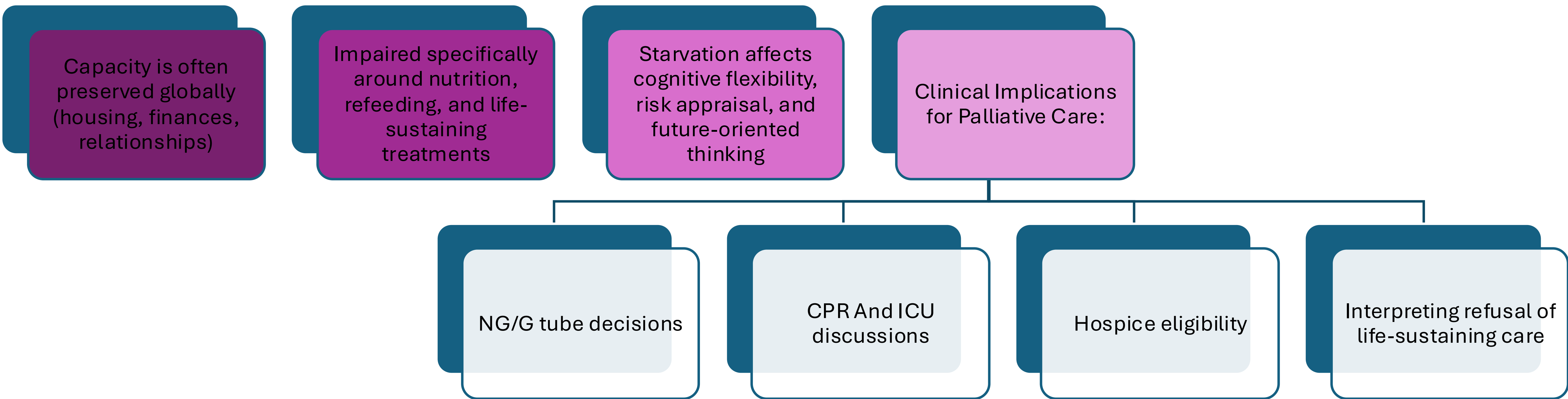
Severe eating disorders challenge traditional models of autonomy, capacity, and beneficence.

- Fluctuating or domain-specific decisional capacity
- Tension between autonomy and perceived self-harm
- High-risk interventions with diminishing proportional benefit
- Moral distress among clinicians and teams

Where Palliative Care Adds Value:

- Nuanced, longitudinal capacity assessment
- Values-based discussions grounded in proportionality
- Support for teams navigating uncertainty and risk

Capacity in Patients with Eating Disorders is Domain-Specific



Capacity in severe eating disorders is frequently domain-specific — not all-or-nothing.

Moral Distress in Severe Eating Disorders

Occurs when clinicians:

- Provide care perceived as harmful
- Repeat non-beneficial interventions
- Feel trapped between autonomy and beneficence

Palliative Care Role:

- Shared responsibility
- Ethical containment
- Narrative reframing

Naming moral distress supports teams and improves care quality.

Common Palliative Care Consult Triggers

Pain (abdominal, musculoskeletal, neuropathic)

Gastrointestinal symptoms and nutritional intolerance

Medical instability and declining functional status

Ethics consultations: goals of care, proportionality, capacity

When Palliative Care could be involved in Patients with Severe Eating Disorders

Consider early involvement when ≥2 are present

- Persistent BMI <13 with complications
- Recurrent admissions without durable recovery
- Refractory symptom burden despite ED treatment
- Repeated coercive feeding
- Family distress or decisional conflict
- Clinician moral injury

Palliative Focus

- Symptom control
- Capacity clarification
- Proportionality of interventions
- Family support

Case Overview: Severe Anorexia Nervosa

Ms. K is a 40-year-old woman with a >25-year history of anorexia nervosa, restricting type. She has had numerous inpatient and outpatient eating disorder admissions and multiple prolonged medical hospitalizations.

Referred to palliative care for:

- Persistent symptom burden despite ED-focused treatment
- Goals-of-care uncertainty in the setting of medical fragility
- Escalating family distress

Ms. K : Symptom Burden

- Neuropathic pain related to edema and refeeding
- Severe anxiety, low mood, and anticipatory fear
- Post-prandial nausea limiting intake
- Frailty and recurrent falls

Ms. K : Psychosocial & Trauma Context Ms. K

- Early childhood trauma
- Eating disorder represents control and identity
- Family tension: protection vs autonomy
- Loss of peers
- Desire for normal adulthood

Ms. K: Disease Severity & Medical Risk

- Extremely low body weight (BMI persistently ~11–12 kg/m^2)
- Recurrent medical complications:
  - Hypoglycemia
  - Electrolyte disturbances
  - Falls, seizures, fractures
  - Pancytopenia and infections
- Multiple incomplete or unsuccessful treatment attempts:
- Inpatient ED programs (voluntary, repeated early discharge)
- Prior NG/G-tube feeding → experienced as highly traumatic and intolerable

Why Palliative Care Was Involved

High medical risk without a clear recovery trajectory
Not end-of-life — but enduring suffering

- Persistent symptom burden despite treatment
- Recurrent hospitalizations without durable improvement
- Severe distress associated with feeding interventions
- Escalating family distress
- Repeated crises in the setting of narrow physiologic reserve

Goals & Tensions

"What Made This Hard"

Patient consistently stated: "I want to live."

- Strong values:
  - Independence
  - Avoidance of coercive feeding
  - Desire to live as long as possible
  - Hope for a family
- Partial insight:
  - Acknowledged illness severity
  - Simultaneous belief in being "invincible"
- Ongoing tension between:
  - Life-prolonging goals
  - Inability to sustain behaviors required for survival
- **Core ethical dilemma:**
  How much treatment is helpful versus harmful?

Treatment Futility ≠ Prognostic Futility

A patient may not be imminently dying, yet specific treatments may no longer provide proportional benefit.

Examples:

- Repeated NG feeds experienced as extremely aversive and distressing and early discharge
- ICU admissions without durable behavioral or medical change
- Refeeding cycles increasing suffering without altering trajectory

Key Concept:

- A treatment can be futile even when death is not imminent.

Focus shifts from prognosis to proportionality.

Ms. K: An Iterative, Non-Linear Process

Early:

- Full code; ICU-level care desired

Over time:

- Increasing recognition of frailty
- Re-evaluation of CPR and intubation risks

Consistent boundary:

- Refusal of NG or G-tube feeding for many years due to severe psychological distress

Later evolution:

- Transition to DNR/DNI
- Openness to comfort-focused care

Planning for Care Without "Giving Up"

Clarifies goals, thresholds, and patient values

Reduces crisis-driven, traumatic care

Supports families experiencing prolonged anticipatory grief

Allows patients to hold dual truths:

- *Hope for recovery*
- *Preparation for deterioration*

An added layer of care focused on dignity, **symptom relief, and alignment**.

TERMINAL ANOREXIA

Arguments you'll hear (pro "terminal AN")

- A small subset has prolonged, severe illness with sustained refusal of further treatment.
- Labeling may reduce moral injury and facilitate hospice-level supports
- May respect autonomy when capacity is intact and treatment is experienced as non-beneficial.

Common concerns (against "terminal AN")

- Prognostic uncertainty — recovery can occur after years.
- Capacity is complex and may fluctuate with starvation and mood.
- Criteria may be overly broad, creating risk for vulnerable patients and inequitable care.

Practical stance for palliative : Focus on goals, capacity, proportionality, and symptom burden — not labels

Recovery Can Still Happen — and Palliation Still Matters

Recovery in ED can occur even after decades due to:

Neuroplasticity

Identity evolution

Relationship changes

Life circumstance shifts

But this does not negate:

Present suffering

Current medical fragility

Need for symptom relief

The appropriateness of hospice if goals shift

Hope for recovery and palliative care are not mutually exclusive.

When Hospice Might Be Considered

- Severe medical decline with goals focused on comfort
- Repeated unsuccessful treatment attempts and sustained, capacitated refusal
- Clear plan for symptom control and family support
- Avoid “terminal” labels as shortcuts—document the reasoning and team consensus

What We Are NOT

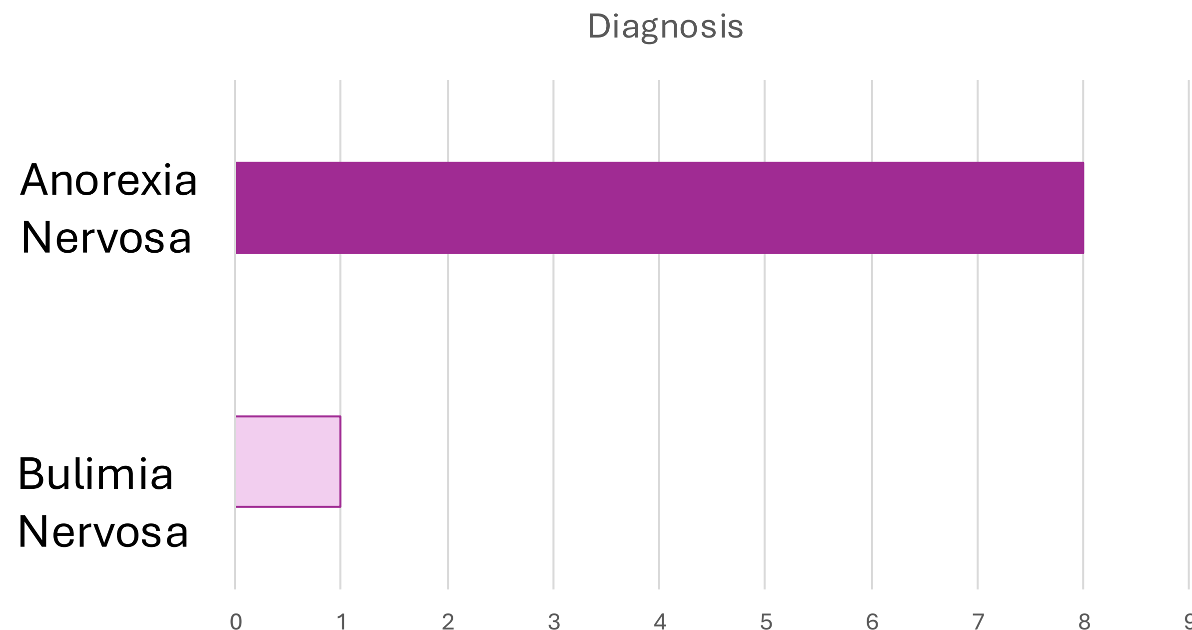
- Not a replacement for ED programs
- Not hospice by default
- Not a MAID assessment
- Not a declaration of futility

The Clinic

A space for patients with severe,
enduring eating disorders
to receive longitudinal supportive care
without abandoning recovery.

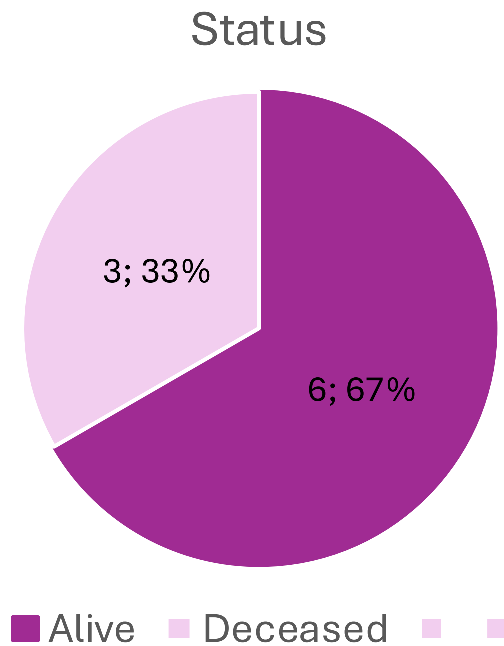
Clinic Demographic Data: 2022 →Present

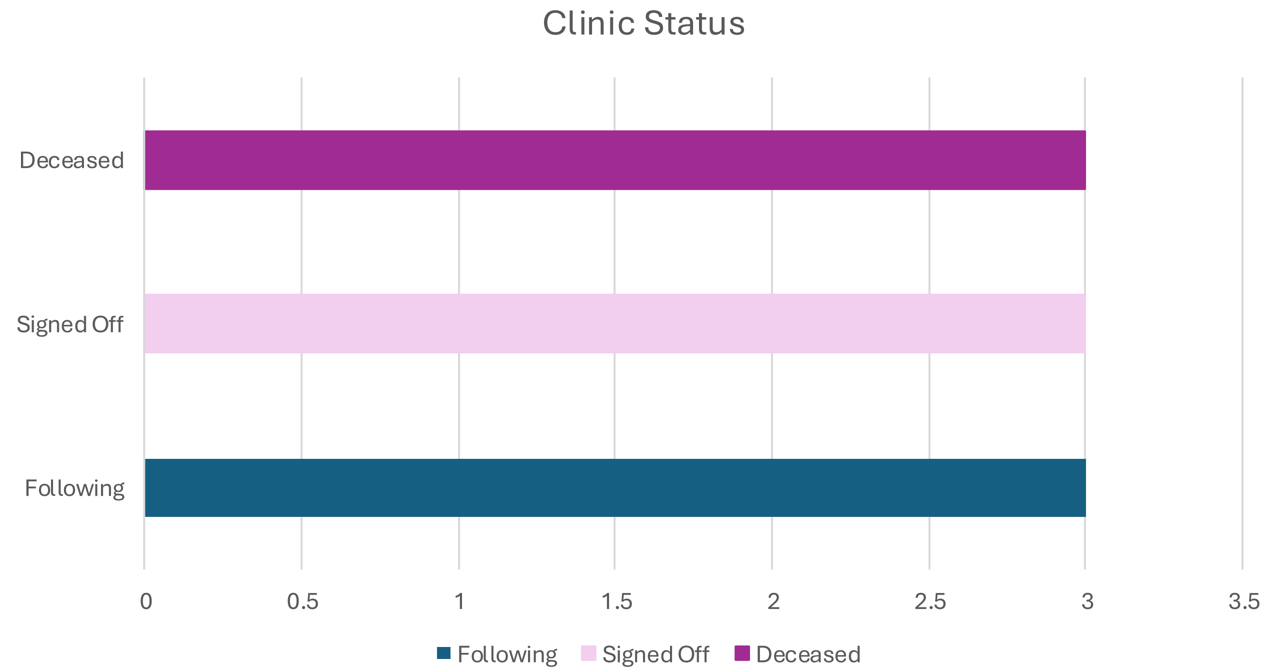
- 9 patients, all female
- Mean age at referral: 34 (range 18–41)
- 100% referred for symptom management and goals-of-care support

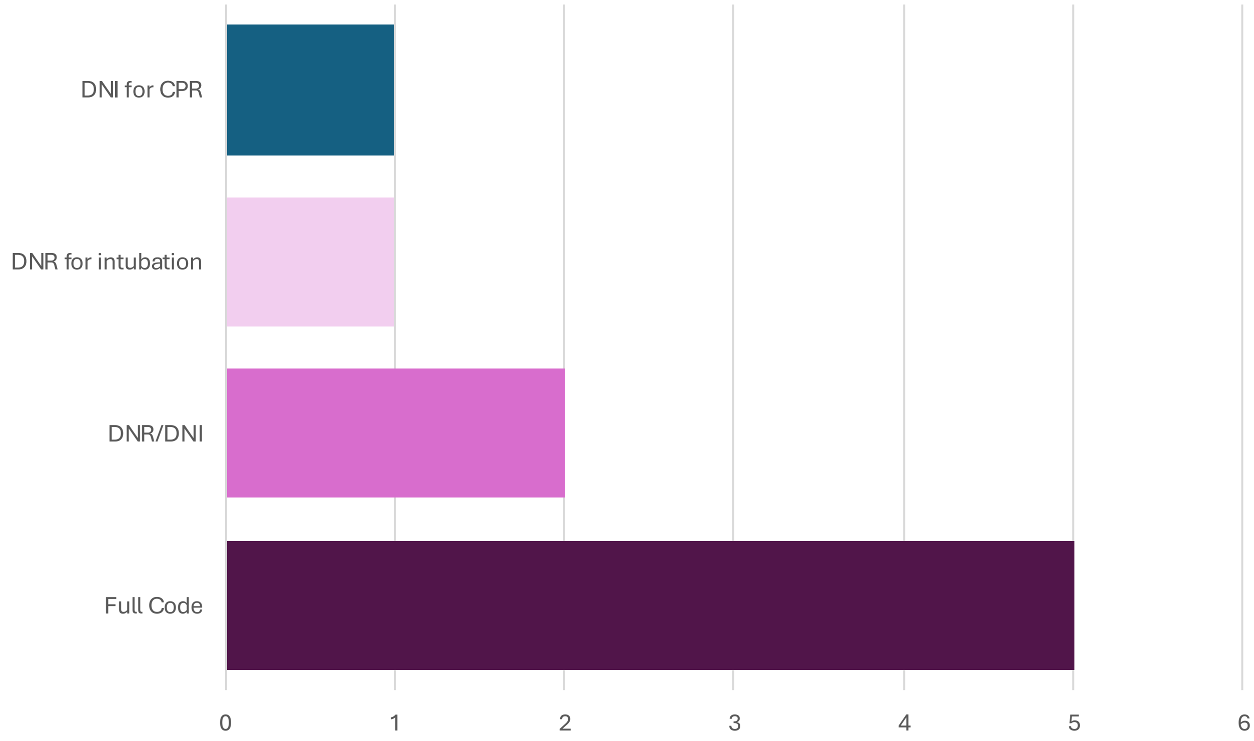


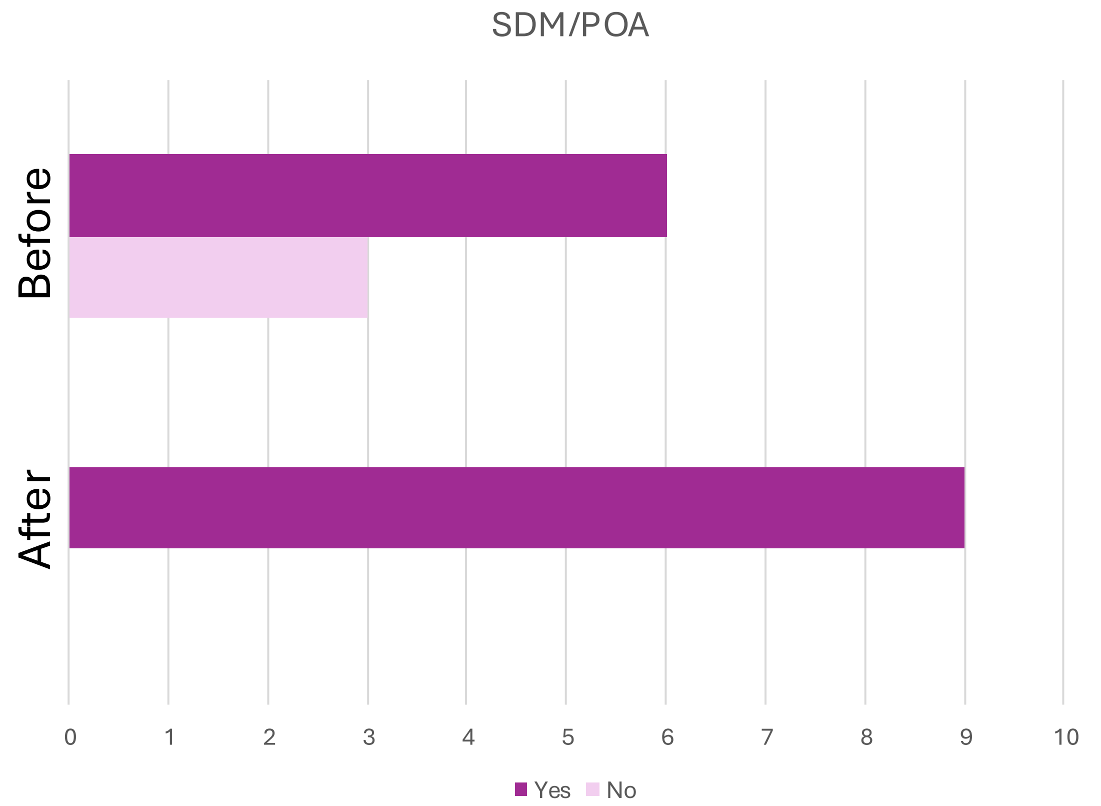
Demographic Data

- Mean age at death: 36 (range 24–43)
- Mean PPS at referral: 64



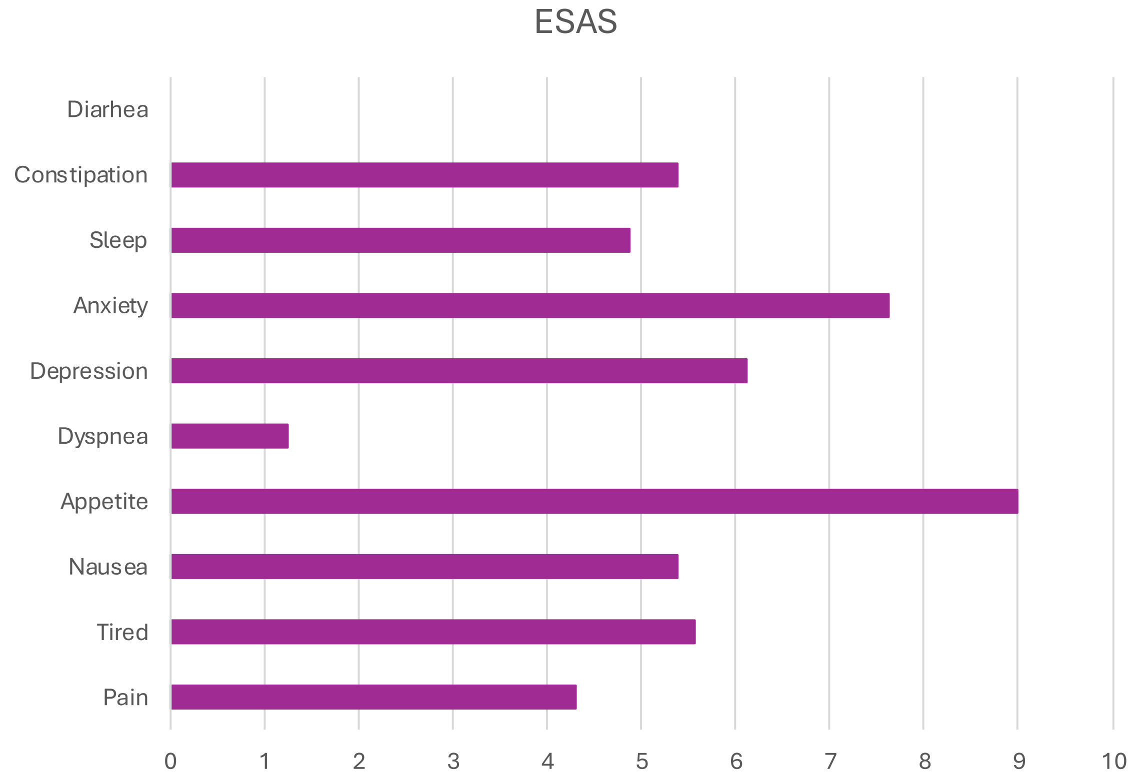






Change in Code Status:
4/9 Full Code → DNR ± DNI
1/9:DNR/DNI → Full Code

Symptoms



Symptom	Medications
Constipation	• Senna • PEG
Pain	• Hydromorphone • Pregabalin • Acetaminophen • Topical Morphine
Nausea	• Metoclopramide • Ondansetron
Sleep	• Zopiclone
Anxiety	• Quetiapine • Lorazepam • Clonazepam • Mirtazapine • Venlafaxine • Sertraline • Fluoxetine • Methylphenidate

NAUSEA

Multifactorial:

- Anxiety-driven anticipatory nausea
- reduced gastric capacity, delayed gastric emptying, constipation
- Electrolyte abnormalities
- Refeeding-related gut edema

Investigate (if clinically indicated)

- Gastric Emptying Study
- Barium swallow

Non- Pharmacological

- Warm liquids before meals
- Small, frequent , low-fat meals

Pharmacological (always check QTc):

- Metoclopramide 5 mg PO QID
- Olanzapine 2.5-5.0 mg PO q8 hours PRN
- Avoid constipating medications (Ondansetron, Dimenhydrinate (Gravol))

⚠ **Important Safety Pearls for AN Population**

•Always correct electrolytes before adding QTc-prolonging meds.

•Avoid dopamine antagonists in severe hypotension.

•Be cautious with polypharmacy — these patients are physiologically fragile.

CONSTIPATION

Multifactorial

- Low oral intake
- Slow colonic transit
- Autonomic dysfunction
- History of stimulant laxative misuse

Investigate

- Abdominal Xray
- Anorectal Manometry

Treatment

- Address hydration and nutrition
- Gentle mobility
- PEG
- Psyllium

Avoid reinforcing stimulant laxative dependence

PAIN

Common Contributors:

- Fluid shifts and refeeding edema
- Prior fractures / osteoporosis
- Sarcopenia and immobility
- Neuropathic pain

Management:

- Evaluate underlying cause
- Heat, compression stockings
- Physiotherapy and mobility support
- Gentle strengthening where possible

Pharmacological:

- Acetaminophen
- Pregabalin (monitor edema)
- Topical Agents: Diclofenac
- Injections
- Avoid opioids

SLEEP

Multifactorial

- Anxiety
- Malnutrition-related sleep disruption
- Depression
- Nocturnal hypoglycemia

Non-pharmacological

- Sleep hygiene
- Cognitive behavioral therapy for insomnia (CBT-I)
- Address underlying contributors

Pharmacologic (Monitor QTc)

- Mirtazapine (Review for duplication with SSRI/SNRI)
- Trazodone
- Low-dose olanzapine (if indicated)

When Anxiety Is — and Is Not — Ours

Back to Ms. K

Clinical Turning Point – Sept 2024

Progressive functional decline

Patient expressed fear of dying

Inability to interrupt compulsive walking and restriction

PPS declined to ~40%

Outcome: Death with Support, Not Abandonment

Progressive medical decline

Transition to hospice

Died peacefully in hospice

Family expressed gratitude for:

Honesty

Consistency

Continuity- not abandonment

What This Case Teaches Us

Severe and longstanding eating disorders can become a life-limiting illness

Palliative care:

- Does **not replace eating disorder treatment**
- Can coexist with hope and ongoing recovery attempts

Palliative Care Contributes:

- Trauma-informed care
- Comfort with uncertainty
- Longitudinal presence

Core Skills

- Reducing suffering
- Supporting dignity
- Walking alongside patients and families

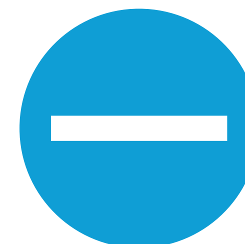
Key Teaching Takeaways

- Capacity in patients with severe and longstanding eating disorders is often domain-specific
- Treatment futility is distinct from prognostic futility
- Recovery potential does not negate the need for palliation
- Early palliative involvement supports patients, families, and teams
- Labels matter less than careful assessment, proportionality, and symptom relief

CLOSING REMARKS

Proportionality.

Presence.



No Abandonment.

Thank you!

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- Department of Medicine

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