Welcome!

We will begin momentarily

Nutrition care at end-of-life

Host: Roslyn Compton

Presenters: Allison Cammer, PhD, RD

Date: 04 September 2025

Territorial Honouring

The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness.

Stay connected: www.echopalliative.com

Thank You

The Palliative Care ECHO Project is supported by a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

Health Canada Santé Canada

Introductions

Host and Moderator

Jodi Hall
CEO, Canadian Association for Long Term Care

Presenters

Allison Cammer, PhD, RD
Associate Professor, Program Director - Dietetics
College of Pharmacy and Nutrition
University of Saskatchewan

Welcome and Reminders

- Please introduce yourself in the chat!
- Your microphones are muted. There will be time during this session for questions and discussion.
- You are also welcome to use the Q&A function to ask questions
- Use the chat function if you have any comments or are having technical difficulties.
- This session is being recorded and will be emailed to registrants within the next week.
- Remember not to disclose any Personal Health Information (PHI) during the session

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Learning Objectives

By the end of the session, participants will be able to:

Discern the role of nutrition in a palliative approach to care

Understand the role of eating and drinking at end of life and on end of life processes

Describe the complexity of clinically administered nutrition and hydration at end of life

Today's Menu

- Background
  - Nutrition in healthcare
  - Palliative and End of Life Nutrition
  - Goals of Care
- Palliative Approach to Nutrition
- Comfort Nutrition/Comfort Feeding
- Role for Artificial Nutrition and Hydration
- Key Takeaways

Palliative Care Principles

Canada's Guiding Principles for Palliative Care:
Palliative Care is Person- and Family-Centred
Death, Dying, Grief and Bereavement are Part of Life
Caregivers are Both Providers and Recipients of Care
Palliative Care is Integrated and Holistic
Access to Palliative Care is Equitable
Palliative Care Recognizes and Values the Diversity of Canada and its Peoples
Palliative Care Services are Valued, Understood, and Adequately Resourced
Palliative Care is High Quality and Evidence-Based
Palliative Care Improves Quality of Life
Palliative Care is a Shared Responsibility

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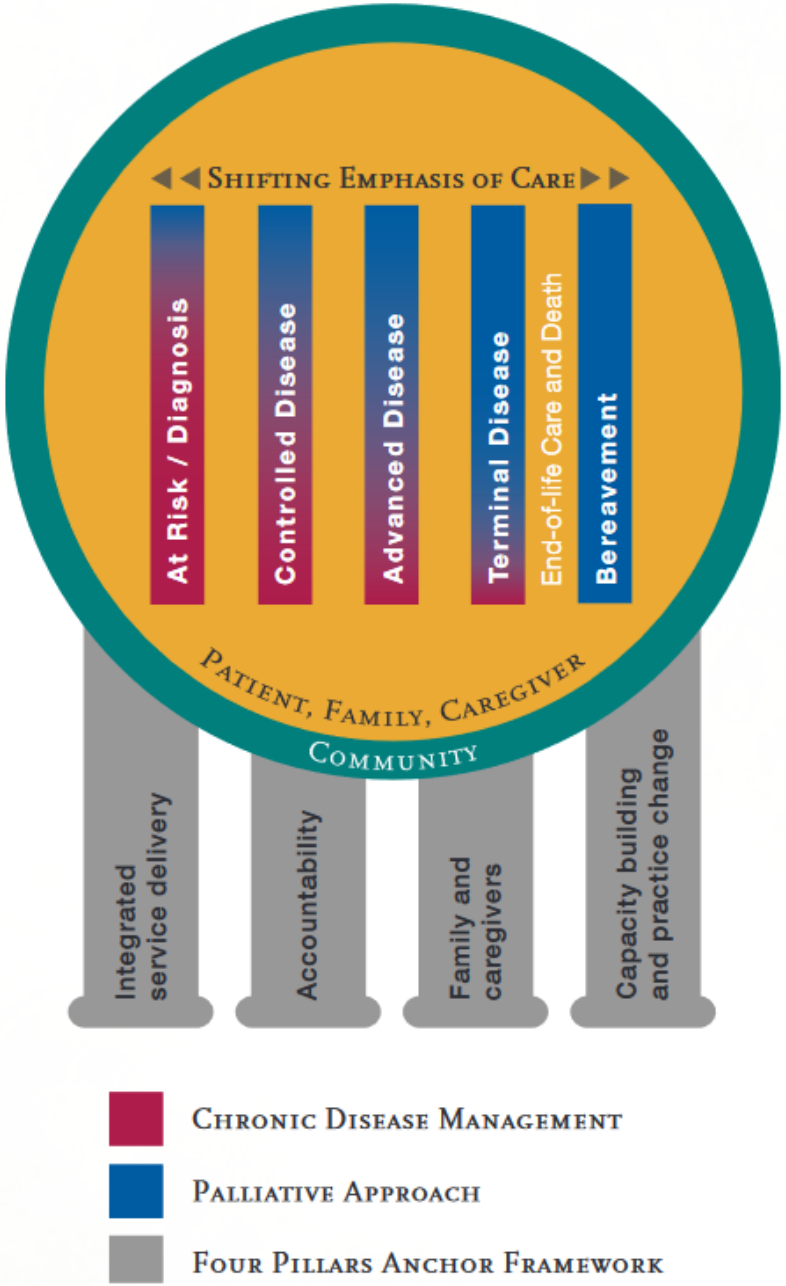
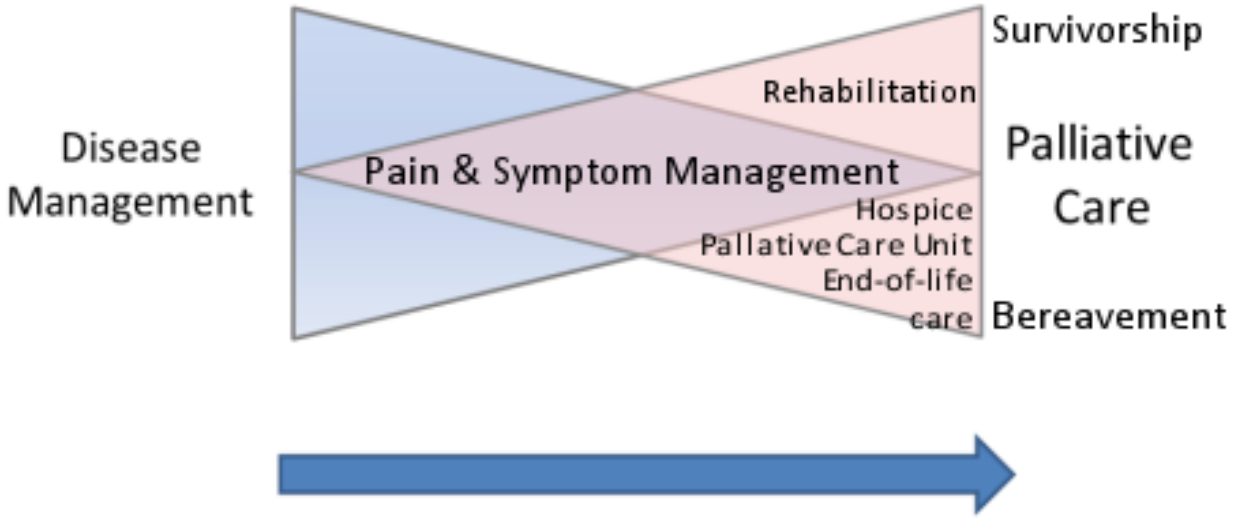
Canada

https://www.canada.ca/en/health-canada/services/palliative-care.html

Nova Scotia Integrated Palliative Care Framework



Palliative Care-Enhanced Model



J Pain Symptom Manage. 2014 Jan;47(1):e2-5. doi: 10.1016/j.jpainsymman.2013.10.009. Epub 2013 Dec 8.

The bow tie model of 21st century palliative care

Philippa H Hawley [1]

Affiliations + expand

PMID: 24321509 DOI: 10.1016/j.jpainsymman.2013.10.009

https://novascotia.ca/dhw/palliativecare/documents/Integrated-Palliative-Care-Strategy.pdf

https://library.nshealth.ca/PalliativeCare/Documents

Additional Competencies for Dietitians with a Practice Focused in Palliative Care [I-II, V-VI, 1-2, 7-12, 21-23, 43, 71-77, 89-100]

Principles of Palliative Care

- Facilitates empathic and responsive relationships between those experiencing life-limiting conditions and their care teams
- Demonstrates leadership that encourages colleagues to foster a caring environment that supports all staff working in sensitive situations
- Applies the Dignity Conserving Care approach when providing support
- Practices person-centred palliative care that incorporates the unique contributions of the family in routine care giving
- Demonstrates an understanding of palliative care standards, norms of practice and best practices
- Demonstrates an advanced knowledge and understanding of the full spectrum of trajectories of life-limiting conditions and their impact on nutritional management when responding to complex and multidimensional care needs

Communication

- Uses a variety of strategies to engage in highly skilled, compassionate, individualized and timely communication with patients, families, caregivers and members of their care teams
- Maintains ongoing communication with the patient, family and their care teams regarding end-of-life plan of care
- Demonstrates expertise as a mediator and advocate for the patient to access appropriate and timely palliative care
- Demonstrates self-awareness of responses to communication challenges and remains engaged in meaningful contact with patients, families and caregivers

Optimizing Comfort and Quality of Life

- Applies a comprehensive understanding of the clinical presentation and disease trajectories of life-limiting conditions when responding to complex and multidimensional care needs, in order to comprehensively identify current and prospective clinical issues in palliative care
- Discusses the benefits and burdens of palliative treatment options to assist the patient in meeting their goals of care
- Contributes to decision making with the patient, family and SDM regarding withdrawing or withholding interventions, while recognizing when to reinitiate interventions
- Acts as an expert resource to other staff regarding the role of discipline-specific interventions in symptom management and optimizing quality of life

Additional Competencies for Dietitians with a Practice Focused in Palliative Care

Care Planning and Collaborative Practice

- Collaborates effectively with the patient, family, caregivers and their care teams to define goals of care and to develop, implement and evaluate a plan of care
- Collaborates with patients and families to identify resources that will provide support during end-of-life care
- Facilitates conversations to support end-of-life decision making
- Identifies patients' and families' values, beliefs and preferences regarding the various components of palliative care provision
- Uses shared scopes of practice to optimize care
- Collaborates within and between teams across the continuum of care to facilitate continuity in palliative care
- Safely and appropriately delegates aspects of care to the family
- Identifies the full range and continuum of palliative care services, resources and the settings in which they are available
  - Demonstrates knowledge of the range of palliative care services and resources
  - Provides relevant information and resources to the patient and family
  - Identifies and accesses services and resources specific to the patient's goals of care
  - Initiates referrals to and requests for resources, services and settings
  - Facilitates patient access to needed services and resources
- Demonstrates an advanced level of discipline-specific clinical expertise in supporting the patient and family to adapt to changing clinical presentation
- Demonstrates an advanced level of clinical expertise and sensitivity in facilitating safe, smooth and seamless transitions of care for patients
- Acts as an expert resource to other staff on the role of dietary and nutritional interventions in symptom management and optimizing quality of life
- Creates a holistic, person-centred plan, acknowledging the psychosocial impact of changing nutritional requirements and dietary intake

Loss, Grief and Bereavement

- Demonstrates a comprehensive knowledge of the grieving process and reactions in order to support patients and families throughout the disease trajectory

Professional and Ethical Practice

- Applies a comprehensive understanding of contemporary legal, ethical and professional standards to the provision of quality palliative care
- Facilitates discussion and resolution of ethical and legal issues in conjunction with patients, families and their care teams
- Actively influences and promotes palliative care strategic initiatives and policy development
- Acts as an expert resource contributing to palliative care development and delivery

Additional Competencies for Dietitians with a Practice Focused in Palliative Care

Education, Research and Evaluation

- Applies knowledge gained from palliative care research
- Where possible, provides the family with opportunities to participate in end-of-life care giving research
- Where possible, leads, facilitates and engages in palliative care education and research
- Critically evaluates outcomes against standards and guidelines
- Contributes to the evaluation of the quality of palliative care and the effectiveness of the Specialist Palliative Care Consult Team
- Educates and mentors patients and families
  - Facilitates patient participation in care planning
  - Identifies and integrates patient strengths in plan of care
  - Safely and appropriately delegates aspects of care to the family
  - Assists the family in care giving and acquiring respite care
  - Engages in family and team conferences
  - Develops a plan of care for the family
  - Develops, facilitates and provides palliative care related education, leadership and mentorship to members of the discipline and students
- Where possible, identifies the opportunities for and barriers to discipline-specific research unique to palliative care

Advocacy

- Advocates for the needs, decisions and rights of patient by recognizing potential vulnerabilities
- Supports autonomous decision-making
- Promotes equitable and timely access to resources
- Advocates for the development, maintenance and improvement of health care and social policy related to palliative care
- Advocates for health professionals to participate in palliative care continuing education opportunities
- Advocates for health professionals to have adequate resource to provide palliative care

Nutrition in Healthcare (Generally)

Each patient/resident/client's nutritional health needs are assessed and attended to; incorporated into nutrition care plan and/or factored into congregate dining plan

The menu is a complex system that operates in the background

- Nutritional adequacy
- Therapeutic requirements
- Taste and enjoyment

Mealtimes frame the day!

Palliative Approach to Nutrition

- **Important to consider the role of food with the person:**
  - Physical Needs
  - Cultural Practices
  - Socialization
  - Source of pleasure
  - Psychological aspects of food and eating

Br J Community Nurs. 2009 Oct;14(10):427-8, 430-1. doi: 10.12968/bjcn.2009.14.10.44494.

Nutrition in palliative care

Sue Acreman [1]

Affiliations + expand

PMID: 19966682 DOI: 10.12968/bjcn.2009.14.10.44494

Palliative Approach to Nutrition

- **Are goals of nutrition care different in a palliative approach?**
  - Dependent on the **stage** and individual's expressed needs
  - What are the person's goals of care?
  - Manage symptoms, enhance remaining life
  - Quality of Life (QoL); socialization and engagement, hedonistic qualities of food and eating
  - Food may be a greater concern than nutrients

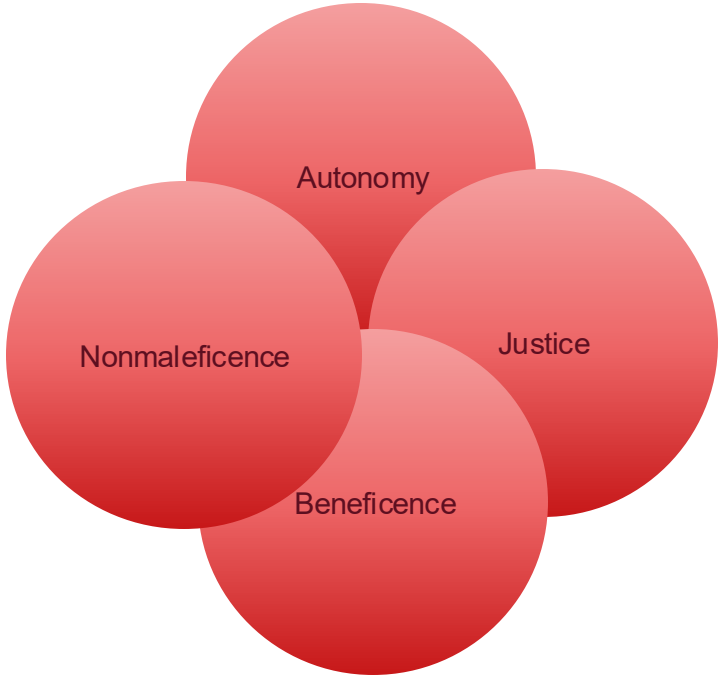
Natural Processes at End of Life

- **Physiological Changes at end of life:**
  - Transition from anabolic to catabolic state
  - Loss of appetite & thirst
  - Redirected blood flow, reduced organ function
  - Decreased gastric volume
  - Decreased gastric emptying and gut motility
  - Fewer bowel movements and less urine output

- **Psychosocial and Behavioural Changes at end of life**

End of Life Nutrition

- When rehabilitative or restorative care is no longer an option and person is in terminal stage, focus shifts entirely to quality of life
- Balancing the beneficial aspects of eating and drinking with detrimental or harmful aspects
  - Very tailored/specific to each person
  - Not as focused on nutrient adequacy
  - Balancing comfort and safety
  - Focus on pleasurable aspects of food and eating



Common **Misperceptions** about End of Life Nutrition

- ‘Food and water are ‘love’ – not pursuing aggressive nutrition care is neglect’
- ‘Loss of appetite and thirst at end of life are signs of depression’
- ‘Starvation/dehydration at end of life is painful, adds to suffering’

We know this, but…

- Nutrition (both eating and hydration) at end of life is a major concern for both loved ones and healthcare providers

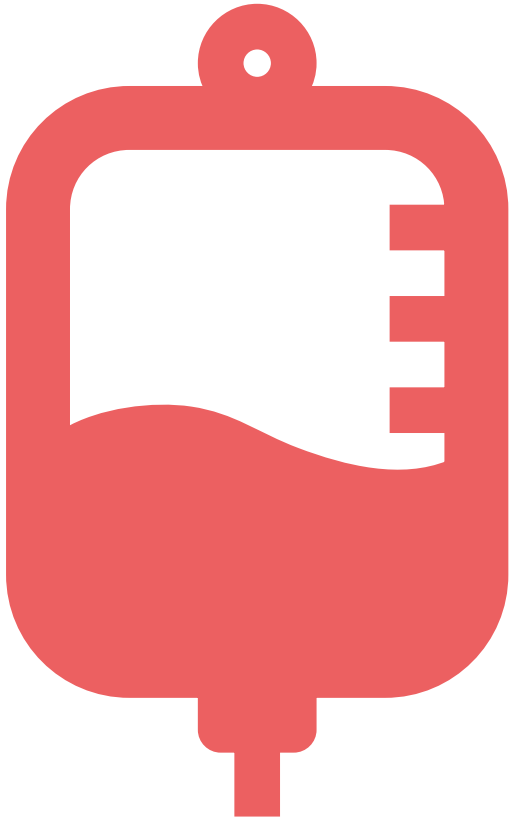
BMC Palliat Care. 2018; 17: 60.
Published online 2018 Apr 16. doi: 10.1186/s12904-018-0314-4
PMCID: PMC5901670
PMID: 29656713

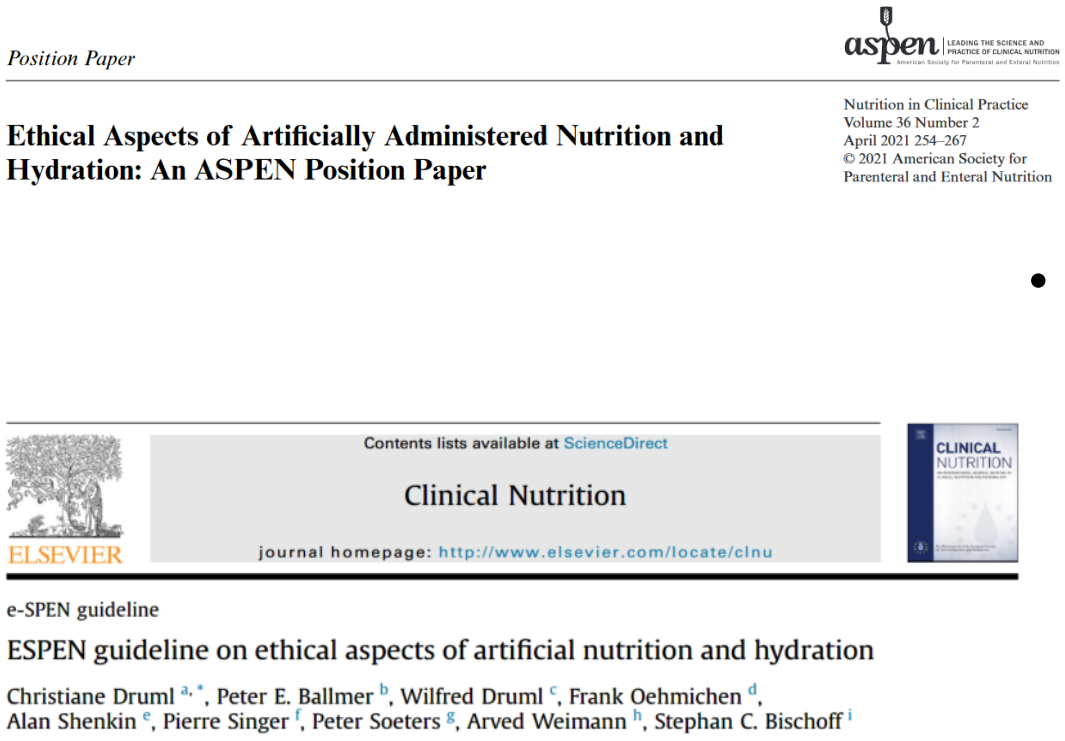
Symptom management, nutrition and hydration at end-of-life: a qualitative exploration of patients', carers' and health professionals' experiences and further research questions

Jessica Baillie,[✉1] Despina Anagnostou,[2] Stephanie Sivell,[2] Jordan Van Godwin,[3] Anthony Byrne,[2] and Annmarie Nelson[2]

Nutrition Care – Aggressive therapy at EOL?

- Artificial Nutrition and Hydration (ANH)
- Medically Administered Nutrition and Hydration
- Clinically Administered Nutrition and Hydration
- Artificially Administered Nutrition and Hydration





Position Paper

Ethical Aspects of Artificially Administered Nutrition and Hydration: An ASPEN Position Paper

aspen LEADING THE SCIENCE AND PRACTICE OF CLINICAL NUTRITION
American Society for Parenteral and Enteral Nutrition

Nutrition in Clinical Practice
Volume 36 Number 2
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Contents lists available at ScienceDirect

Clinical Nutrition

journal homepage: http://www.elsevier.com/locate/clnu

ELSEVIER

CLINICAL NUTRITION

e-SPEN guideline

ESPEN guideline on ethical aspects of artificial nutrition and hydration

Christiane Druml [a, *], Peter E. Ballmer [b], Wilfred Druml [c], Frank Oehmichen [d], Alan Shenkin [e], Pierre Singer [f], Peter Soeters [g], Arved Weimann [h], Stephan C. Bischoff [i]

- What does ANH refer to?
- NIH definition: "ANH refers to nutrition and hydration provided through artificial means such as feeding tubes (eg, nasogastric and gastric tubes) and intravenous routes (eg, total or partial parenteral nutrition)."
- ESPEN definitions:
  - AN includes ONS, EN or PN. Enteral delivery of nutrients includes nasogastric and nasogastrojejunal tubes or percutaneous endoscopic gastrostomy (PEG) or jejunostomy (PEG-J) or surgically induced feeding tubes. Parenteral delivery can involve peripheral intravenous access or central venous access.
  - AH: provision of water or electrolyte solutions by any other route than the mouth. This can be achieved by tubes, intravenous and subcutaneous (=dermoclysis) administration.

Criteria to d/c ANH?

- Short life expectancy (~2 months)
- Use of performance status scales
- Severe organ failure
- Pain
- Discomfort/interference with function
- Patient/resident decision

Performance Status Scales

Zubrod Scale		Karnofsky Scale	
0	Normal activity	100	Normal; no evidence of disease
		90	Able to perform normal activities with only minor symptoms
1	Symptomatic and ambulatory; cares for self	80	Normal activity with effort; some symptoms
		70	Able to care for self but unable to do normal activities
2	Ambulatory >50% of time; occasional assistance	60	Requires occasional assistance; cares for most needs
3	Ambulatory ≤50% of time; nursing care needed	50	Requires considerable assistance
		40	Disabled; requires special assistance
		30	Severely disabled
4	Bedridden	20	Very sick; requires active supportive treatment
		10	Moribund

JAMA Oncology 2015; 1: 998

What factors are involved in decisions around clinically-administered/ artificial nutrition and hydration at end of life?

- Cultural beliefs
- Legal/ethical
- Personal; Unclear plan – not sure what person's wishes are
- Symbolic value
- Perception of "starving to death"
  - For many, food/eating/sustenance is synonymous to care
  - Often think of the benefits of artificial nutrition, often unaware of the negatives
  - Myths surrounding withdrawing artificial nutrition
  - Myths surrounding dehydration at terminal phase
- Discontinuing can be difficult: "Look at the whole person, not the hole in the person"

European Society for Parenteral and Enteral Nutrition – Practice Guidelines

ESPEN: “The worldwide debate over the use of ANH remains controversial although the scientific and medical facts are unequivocal. ANH are a medical intervention, ***requiring an indication, a therapeutic goal, and the will (consent) of the competent patient***.”

https://www.espen.org/files/ESPEN-Guidelines/3__ESPEN_guideline_on_ethical_aspects_of_artificial_nutrition_and_hydration.pdf

Clinically Assisted/Artificial Nutrition – EOL complicated and sometimes controversial

Reasons to choose NOT TO provide:

- Limits mobility
- Can limit positioning
- Can interfere with sleep
- Discomfort of AN site
- Discomfort of AN provision
- Mechanical complications/irritations (site of placement, healing, tube occlusion/injury)
- Risk for aspiration
- Reduction in gastric volume and gastric peristalsis plus reduced intravascular volume increases risk of aspiration, nausea/vomiting, edema, ascites, diarrhea
- Increased need for bowel care
- Patient/family beliefs

Reasons to choose TO provide:

- Can help some people feel comfortable
- Specific goal
- Patient/family beliefs

Clinically Assisted/Artificial Hydration – EOL complicated and sometimes controversial

Reasons to choose NOT TO provide:

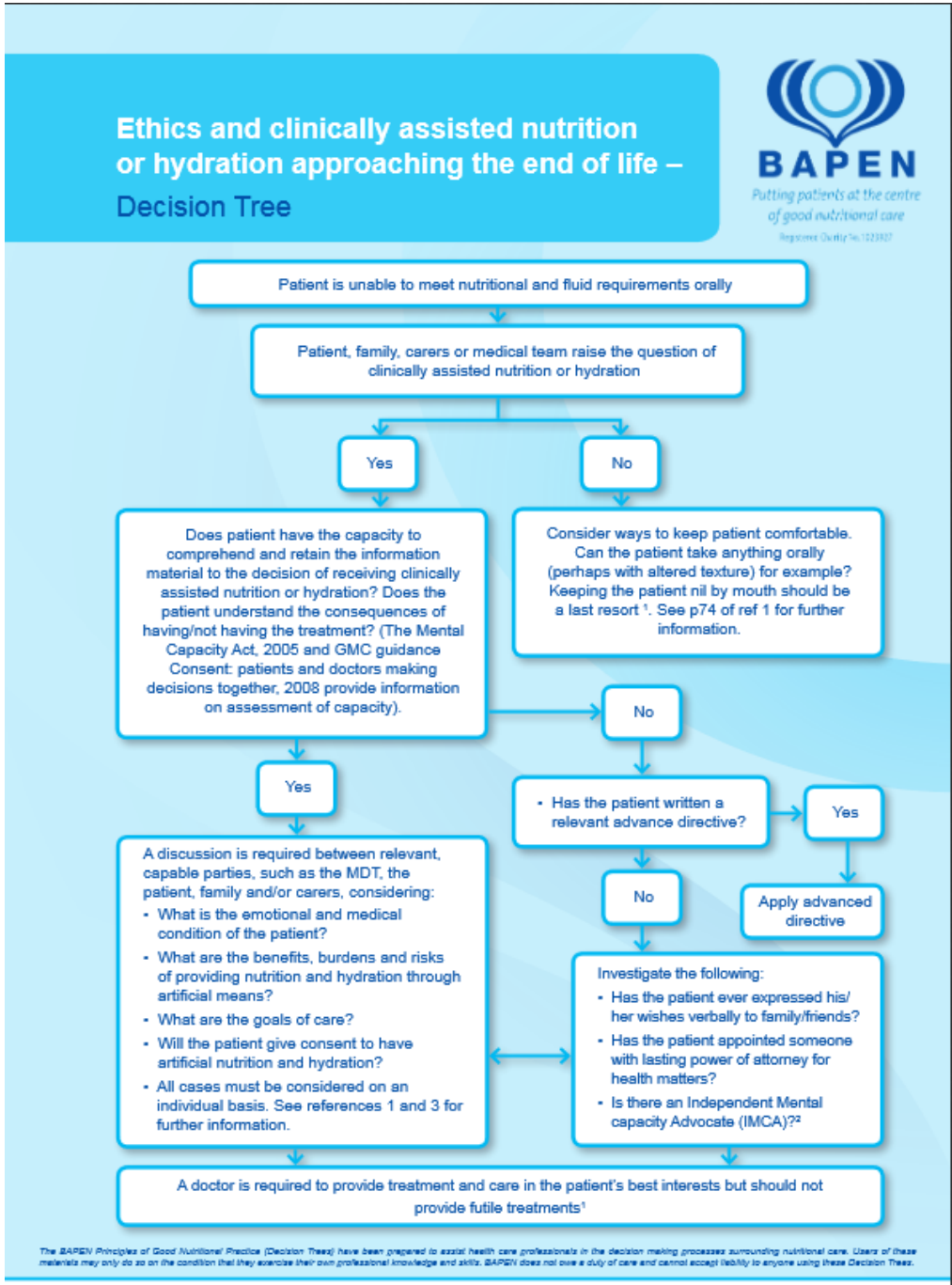
- Can limit mobility
- Can prolong dying, doesn't prolong life
- Discomfort of AH provision
- Mechanical complications/irritations
- Can cause diarrhea for some
- Fluid deficit can reduce pulmonary edema and cough, decrease edema and ascites, reduce nausea and/or vomiting
- Fluid deficit can reduce need for toileting assistance/incontinence/catheters
- Dehydration can provoke a natural anesthetic (azotemia, hypercalcemia, hypernatremia); can increase comfort
- Patient/family beliefs

Reasons to choose TO provide:

- Dehydration can increase restlessness, confusion, and neuromuscular irritability
- Hydration status and pharmacological pain management
  - Decreased intravascular volume and GFR due to fluid deficit → opioid metabolites accumulate (confusion, myoclonus, seizures)
- Can relieve feelings of thirst for some*
- Can aide in preventing/treating delirium
- Can help some people feel comfortable
- Patient/family beliefs

https://www.bapen.org.uk/resources-and-education/education-and-guidance/bapen-principles-of-good-nutritional-practice

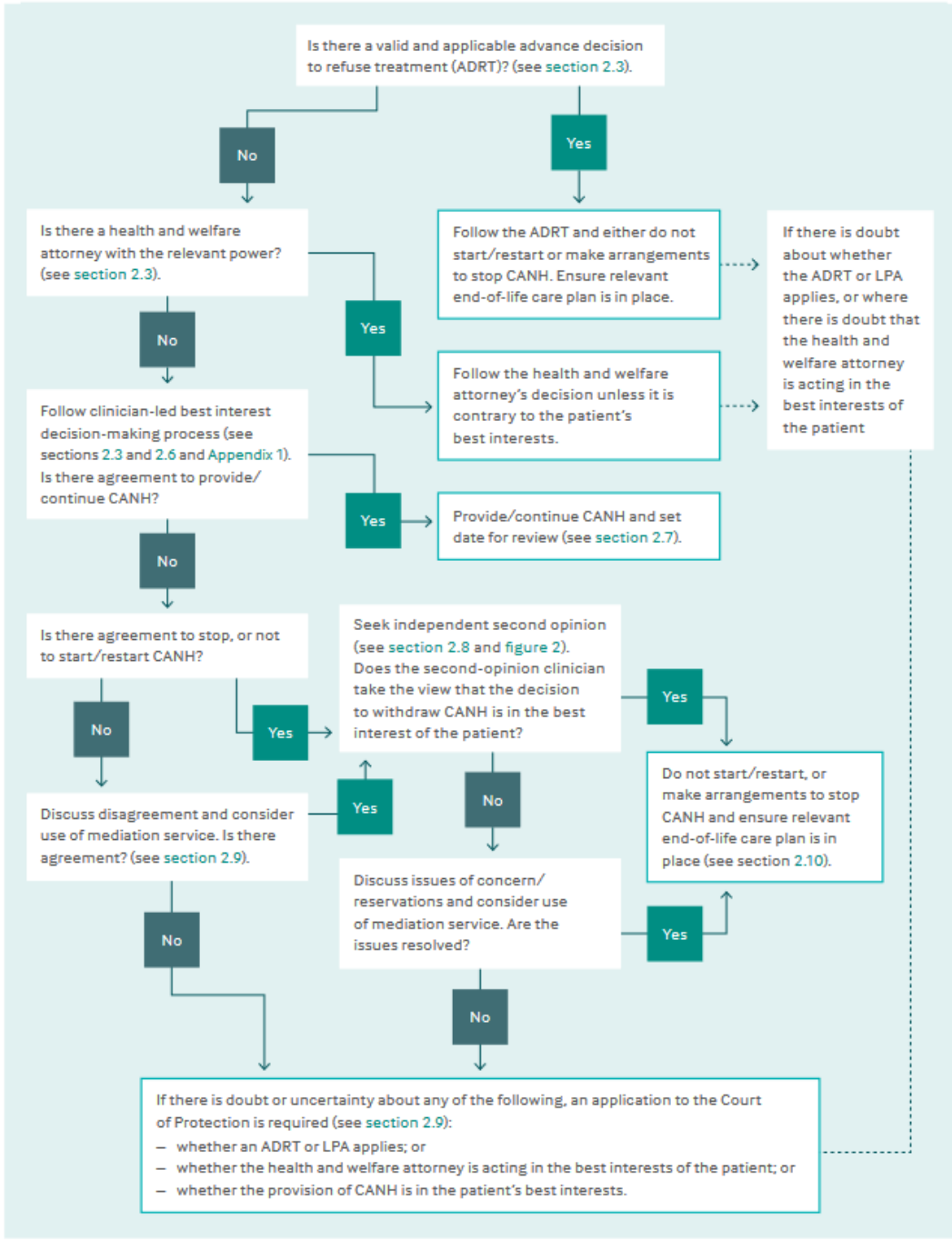
(Decision tree from 2012 version –web resources updated in 2023)



BAPEN – BMA 2023 update

https://www.bma.org.uk/advice-and-support/ethics/adults-who-lack-capacity/clinically-assisted-nutrition-and-hydration

Decision making process summary, Page 12



Project ECHO Palliative Care - Canada BY Pallium Canada CGNA Canadian Gerontological Nursing Association

ANH/CANH at EOL

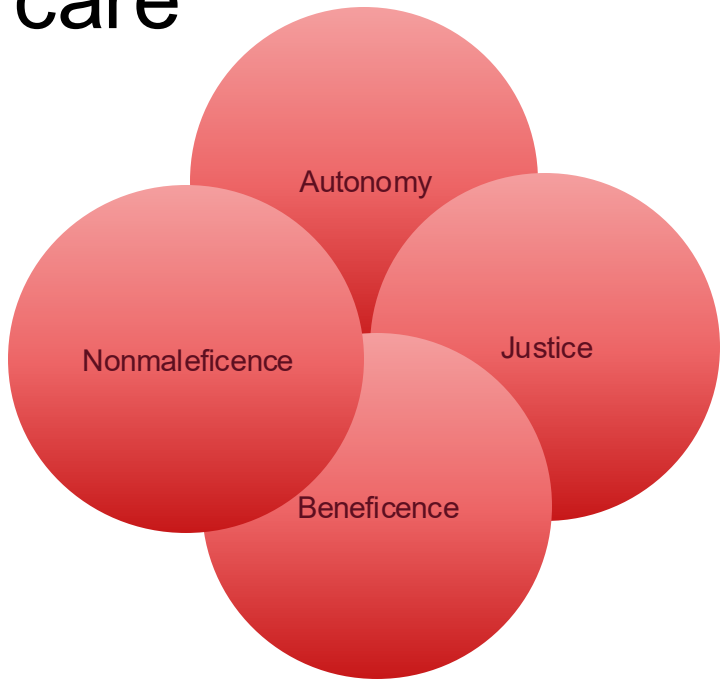
Complex Issue

Multifactorial

Generally not recommended for EOL care

We know this, but…

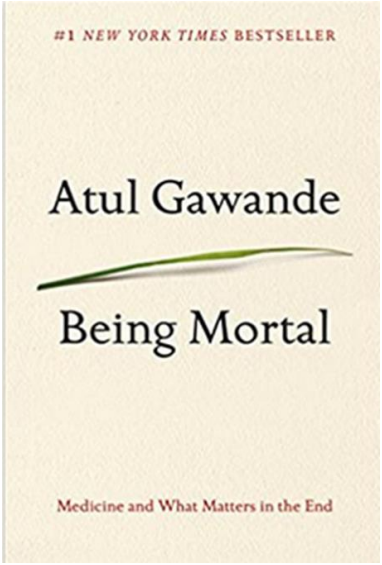
- Abrupt change in the nutritional goals of care
- Tough time of it in the moment
  - Acceptance of dying
  - Role
  - Personal beliefs about dying
  - Individual desires
- Ethical practice



What can help? Shift perspective…

- Healthcare providers try to provide patients as much freedom from the effects of disease as possible while retaining enough function for active engagement in the aspects of life most important to them (preserving the abilities the patient/resident/client deems most important at that time)
- Perspective matters → what makes life significant?
  - Very personal; Autonomy, dignity, purpose/engagement
- Important not to confuse **treatment** with **care**

-Dr. Atul Gawande



Comfort Nutrition and End of Life

Next Week!

Thank You

Project ECHO® Palliative Care - Canada BY Pallium Canada

CGNA Canadian Gerontological Nursing Association

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