A Palliative Approach to Advanced Non-Malignant Disease

Renal, Cardiac, and Pulmonary Care

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New Brunswick Hospice Palliative Care Association (NBHPCA) Conference

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Presentation Objectives

- Describe the role of palliative care in managing chronic lung, heart, and renal disease
- Understand evidence-based strategies to optimize care using a palliative lens
- Promote awareness of palliative care benefits among patients, families, and healthcare teams

Why Palliative Care?

Case: Mr. L, 76-year-old with advanced COPD, CHF, and CKD (GFR 14)

Mr. L is a retired mechanic with progressive dyspnea on minimal exertion. He lives with his wife in a rural community and has been hospitalized four times in the past year — for volume overload, hypercapnic respiratory failure, and uremic symptoms. He now requires home oxygen, takes 14 medications, and reports severe fatigue, poor appetite, and worsening anxiety.

His nephrologist feels dialysis is not appropriate due to frailty. His cardiologist has exhausted medical therapy. He and his wife are overwhelmed by complex care needs and conflicting messages from specialists.

The Hidden Burden of Non-Malignant Disease

While often less visible, the symptom burden in non-cancer patients is comparable to that experienced by patients with advanced cancer (Moens et al., 2014; See et al., 2022).

Common Symptoms Include:

- Persistent pain
- Fatigue that limits daily activities
- Breathlessness, even at rest
- Emotional and psychological distress, such as anxiety or depression

Patients with non-cancer illnesses are also more likely to:

- Be of older age
- Have multiple chronic conditions (multi-morbidity)
- Be frail or at risk of rapid functional decline
- Live with a lower baseline functional status

Barriers to Accessing Palliative Care in Non-Cancer Populations

Misconceptions About Palliative Care

– Belief that palliative care is only for end-of-life

– Assumption that it cannot be provided alongside active treatment

(Collins et al., 2020)

Lack of Standardized Referral Criteria

– No consistent guidelines for when to refer to palliative care

– Referral practices vary between institutions and specialties

(Etkind et al., 2017)

Limited Awareness Among Healthcare Providers

– Many clinicians are unfamiliar with local palliative services and referral processes

(Sawhney et al., 2022)

Concerns About Patient Perception

– Fears that referral may be perceived as abandonment or giving up hope

(Collins et al., 2020)

Our Role in Non-Cancer Palliative Care: A Dynamic & Evolving Approach

The functional trajectories in non-malignant illness — such as advanced heart failure, COPD, or dementia — differ significantly from cancer or sudden death.

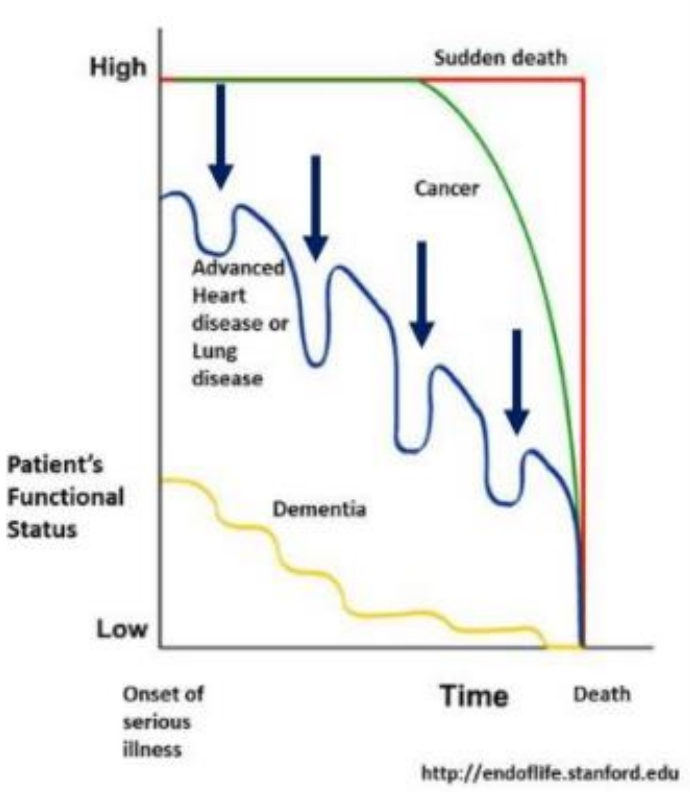
This graphic (Stanford, endoflife.stanford.edu) illustrates these varied paths:

Cancer (green line): Often a more predictable decline with a clear terminal phase.

Advanced organ failure (blue line): Marked by cycles of decline and recovery, creating uncertainty in prognosis and timing of palliative needs.

Dementia (yellow line): A slow, steady decline with high caregiver burden and prolonged needs.

Sudden death (red line): Unexpected with minimal functional decline prior to death.



Palliative care in non-cancer illness is not linear — **our role must adjust over time.**

Requires a flexible and layered approach that adapts as the patient's needs evolve.

Our involvement is influenced by:

- Ongoing Goals of Care and Advance Care Planning
- Prognostic clarity (or lack thereof)
- Collaboration with specialists and primary care
- Shifting patient and family needs across the disease trajectory

Integration at Key Points in the Disease Trajectory

Three critical windows where a palliative care approach can make a meaningful difference in patients with non-malignant illnesses:

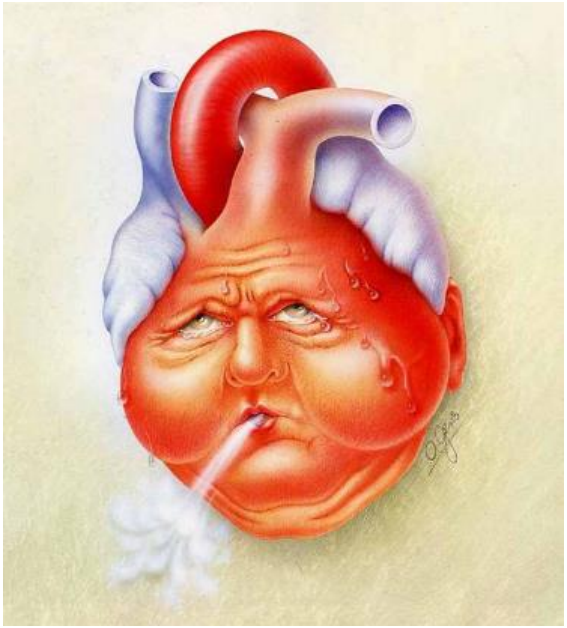
1. Post-Hospitalization Recovery

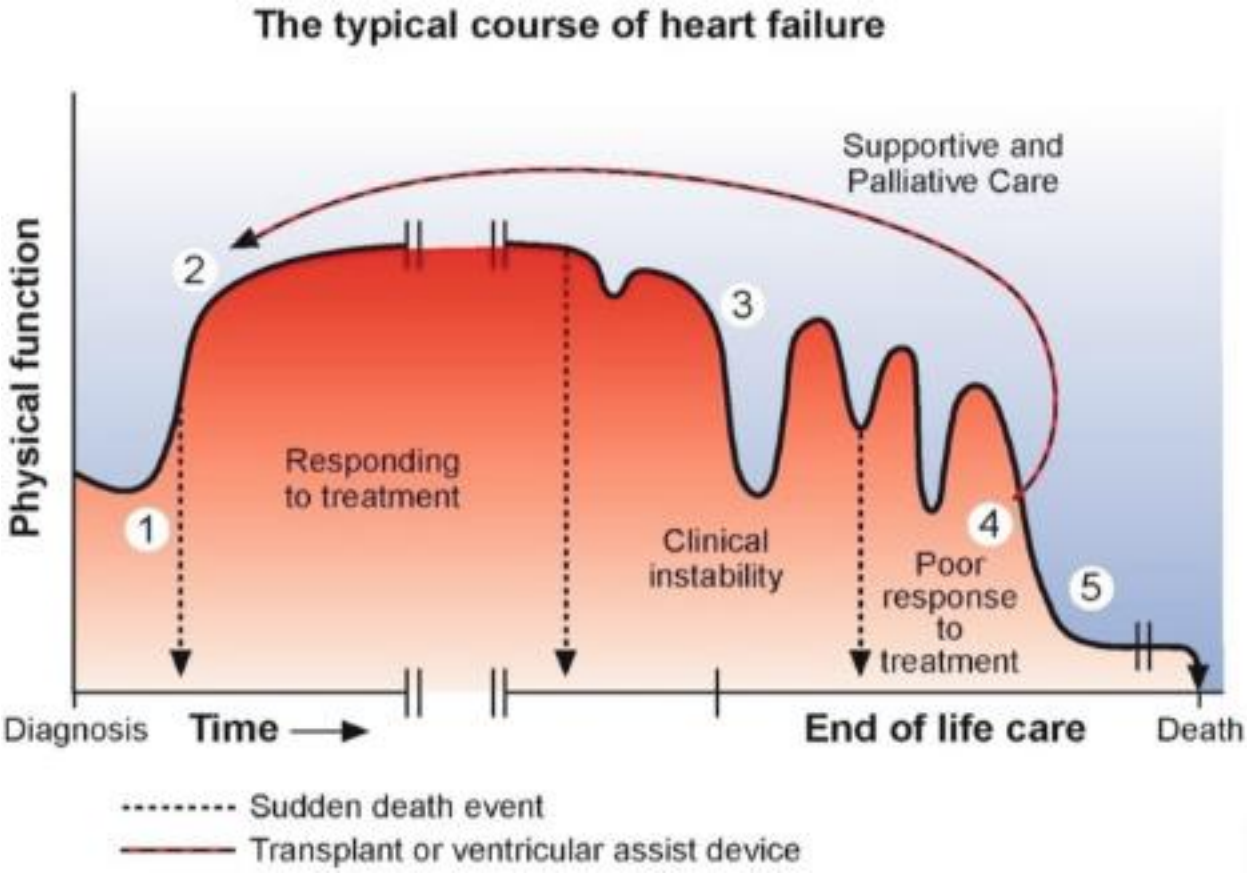
2. Refractory Symptom Crises

3. Transition to End-of-Life Care

The Burden of Heart Failure in Canada

- Over **750,000 Canadians** are currently living with heart failure, with more than **100,000 new cases diagnosed annually** (Heart & Stroke Foundation, 2022).
- Prevalence increases with age; n**early 1 in 5 people over the age of 80 are affected** (HeartLife Foundation, 2024).
- Heart failure is among the **leading causes of hospitalization** for Canadians over age 65 (Canadian Cardiovascular Society).
- It contributes to over **$2.8 billion annually in direct healthcare spending, largely due to frequent hospital admissions** (Tran, Ohinmaa, & Thanh, 2016).
- In the final 6 months of life, individuals with heart failure often experience high resource use with repeated hospital visits and admissions (Kaul, McAlister, & Ezekowitz, 2011).
- Despite this burden, less than 10% of patients with advanced heart failure in Canada receive timely palliative care (HeartLife Foundation, 2024).





Note: The diagram is widely adapted and used in palliative care presentations, sometimes attributed to the Heart Failure Society of America and Stanford Medicine's End-of-Life Education resources.

Krumholz, H. M., Curtis, J. P., Hammes, B. J., Lin, Z., & Konetzka, R. T. (2008). Integrating palliative care in heart failure: The trajectory of illness and

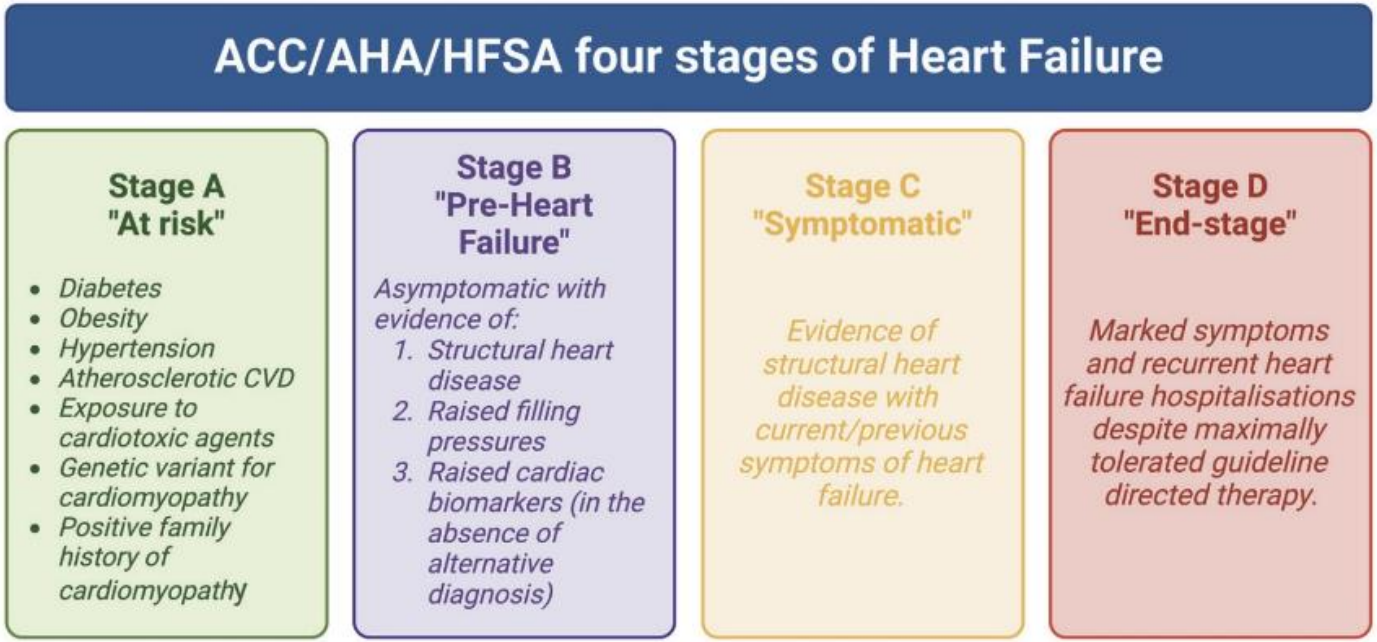
NYHA classifications

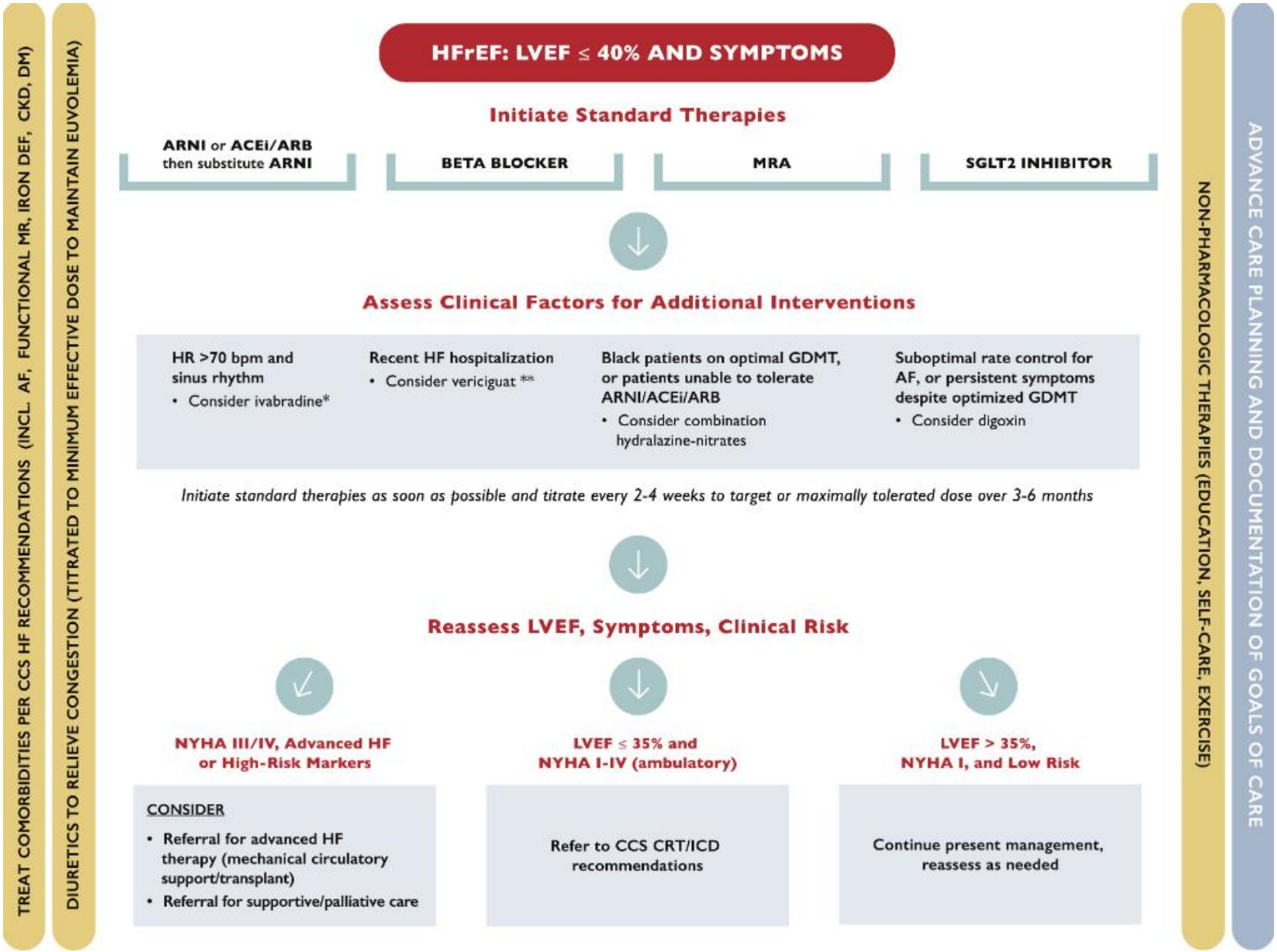
The New York Heart Association (NYHA) classifies heart failure based on symptoms and physical activity limitations.

Class I	• No symptoms • No limitation in routine physical activities • No dyspnea with walking, stair climbing, etc.
Class II	• Mild symptoms (mild dyspnea, angina) • Slight limitations of ordinary physical activity
Class III	• Marked limitation in physical activity due to symptoms • Symptoms occur with less than ordinary activity (walking a short distance) • Comfortable only at rest
Class IV	• Severe physical limitations • Symptoms occur while at rest • Primarily bedbound

Source: American Heart Association 2017

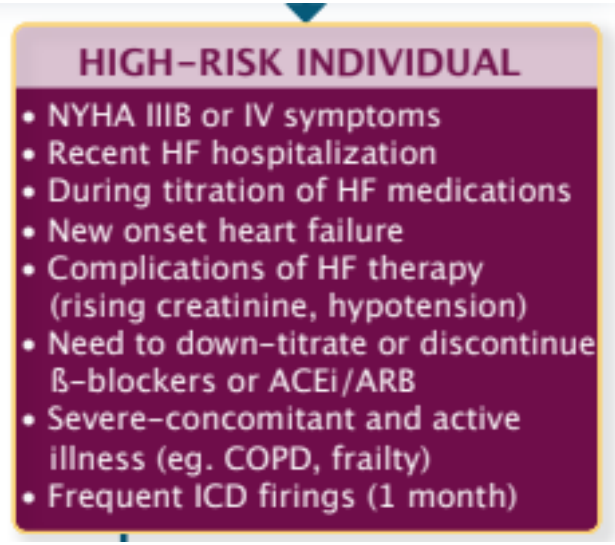
Figure 1. The four-stage heart failure continuum as described by the American College of Cardiology (ACC)/American Heart Association (AHA)/ Heart Failure Society of America (HFSA).[10]





Sidhu, K., Young, A., Ma, W., Rayson, D., & Pollak, P. T. (2021). Integration of palliative care in heart failure: Rationale, evidence, and implementation. Canadian Journal of Cardiology, 37(9), 1352–1361. https://doi.org/10.1016/j.cjca.2021.01.020

Canadian Cardiovascular Society



21). 2021 CCS heart failure guidelines update: Focus on transitions, comorbidities, and advanced care. https://ccs.ca/wp-content/upload

CRT and ICD Use in HFrEF

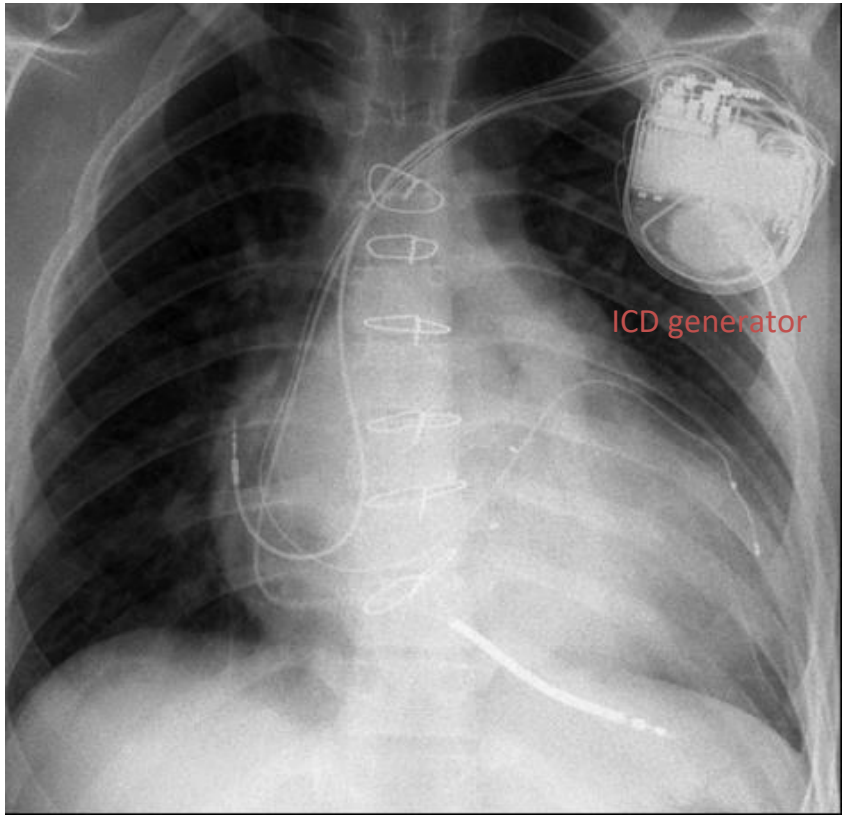
Cardiac Resynchronization Therapy (CRT):

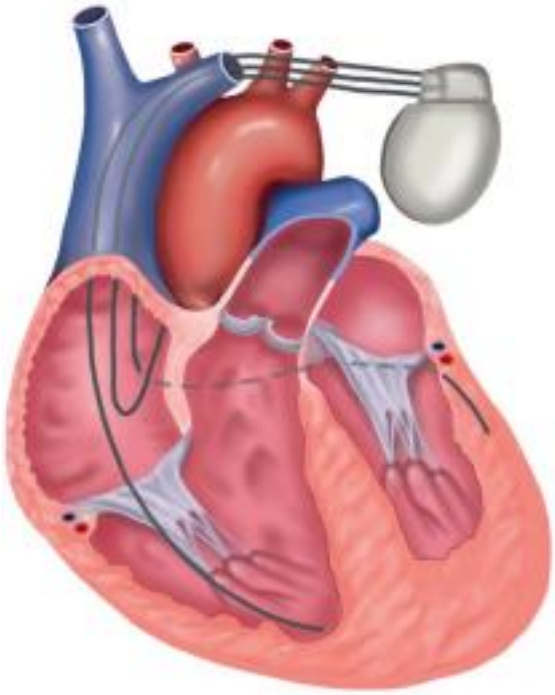
- Indication: Symptomatic HFrEF (EF ≤35%) with LBBB and QRS ≥130 ms despite optimal medical therapy
- Benefit: Improves ventricular synchrony, symptoms, and quality of life; reduces hospitalization and mortality

Implantable Cardioverter Defibrillator (ICD):

- Indication: HFrEF (EF ≤35%) with expected survival >1 year and NYHA II–III symptoms despite medical therapy
- Purpose: Prevents sudden cardiac death from ventricular arrhythmias

CRT-ICD in HFrEF





From: Nemer DM et al. JACC: Clinical Electrophysiology. 2021 Jan 1;7(1):62-72.

CCS HF 2017

Pharmacologic Management of HFpEF

🎯 **Goals:** symptom relief, reduce hospitalizations, manage comorbidities

✔ **SGLT2 Inhibitors (empagliflozin, dapagliflozin)**

Reduce hospitalizations and improve quality of life. Benefit regardless of diabetes status.

✔ **Diuretics (furosemide, torsemide)**

Used to manage fluid overload. No mortality benefit but essential for symptom control.

✔ **MRAs (spironolactone)**

May reduce hospitalizations (TOPCAT trial). Monitor potassium and renal function.

✔ **Beta-blockers, ACEi/ARBs**

Use if comorbid conditions are present (e.g., hypertension, atrial fibrillation, coronary artery disease). Limited HFpEF-specific benefit.

✔ **ARNI (sacubitril/valsartan)**

May provide modest benefit in select patients, especially those at the lower end of the preserved EF spectrum.

Triggers for Specialist Palliative Care Consultation in Heart Failure

- Recurrent hospitalizations despite optimal therapy
- Persistent symptoms (e.g., dyspnea, pain, fatigue, depression)
- NYHA Class III–IV functional status
- Progressive decline in function or weight loss (cardiac cachexia)
- Complex decision-making needs, especially around device therapies (ICD, LVAD)
- Advanced care planning needs not yet addressed
- Frequent ED visits or acute care use
- Significant caregiver distress or inadequate support

(Adapted from Box 23.1, Palliative Medicine: A Case-Based Manual)

Palliative Integration in Heart Failure: A Long-Term Partnership

- Heart failure is a **chronic, progressive condition** with unpredictable episodes of decline

- Patients may **respond to treatment intermittently**, but function typically worsens over time

- **Sudden cardiac death** is possible at any stage — even when function appears preserved

- **Palliative care should begin early** and evolve alongside cardiology care

Focus areas include:

- Symptom relief (dyspnea, fatigue, edema)
- Advance care planning & device discussions
- Support during hospitalizations and recovery phases
- End-of-life care when treatment options are exhausted

Managing Dyspnea, Fatigue, and Fluid Overload

Dyspnea Management

- Low-dose opioids: Hydromorphone 0.5–1 mg or Morphine 2.5–5 mg PO
- Pursed-lip breathing & positioning
- Energy conservation (OT support, home modifications)

Fluid Overload & Diuretics

- Furosemide up to 400 mg/day PO/IV/SC
- Bolus or continuous infusion (10–20 mg/hr common)
- **Add-ons for diuretic resistance:**
- HCTZ (25–200 mg), Spironolactone (12.5–100 mg)
- Metolazone (5–20 mg) vs Acetazolamide (250–500 mg)
- Monitor electrolytes if death is not imminent

Managing Dyspnea, Fatigue, and Fluid Overload

♡ **Ongoing CHF Management**

- Continue beta blockers as it reduces catecholamines
- Consider IV inotropes: dobutamine, milrinone
- Avoid NSAIDs (risk of fluid retention, ↓ GFR)
- Use opioids for cardiac ischemia or chronic pain
- Scheduled acetaminophen often underused but effective

🧠 **Depression & Fatigue-Related Distress**

- Sertraline (Zoloft): safe SSRI (25–200 mg/day)
- Psychosocial support and counseling

Table 23.1 Common ambulatory heart failure symptoms and associated management

	Symptom	Pharmacological	Non-pharmacological
Traditional HF symptoms	Dyspnoea	• Optimized HF therapy (as per CCS guidelines) • Inotropic agents (if consistent with goals of care) • Consider subcutaneous furosemide • Consider psychotropic: - First line: low-dose opioids - Second-line: benzodiazepines	• Rehabilitation/physical activity • Energy conservation • Positioning • Supplemental oxygen if hypoxic • Fan to circulate air
	Fatigue	• Optimized HF therapy (as per CCS guidelines)	• Rehabilitation/physical activity • Consider depression, sleep disordered breathing, or other comorbidities
	Oedema	• Optimized HF therapy (as per CCS guidelines)	• Attention to skin care
Gastrointestinal symptoms	Nausea	• Optimized HF therapy (as per CCS guidelines) • Promotility agents (metoclopramide) • Haloperidol • Ondansetron	• Small frequent meals
	Constipation	• Stimulant laxative (sennosides)	• Relax fluid restriction
	Abdominal fullness/ distension	• Intensify diuresis if ascites present	
Central nervous system symptoms	Depression	• Optimized HF therapy (as per CCS guidelines) • Selective serotonin reuptake inhibitors (sertraline, citalopram) • Avoid tricyclic antidepressants	• Psychotherapy • Cognitive behaviour therapy • Rehabilitation/physical activity
	Anxiety	• Consider and treat concomitant depression	• Supportive/psychotherapy • Breathing exercises • Relaxation therapy • If related to ICD discharge, consider psychiatry review and adjusting settings or deactivation
	Sleep disturbance	• Optimized HF therapy (as per CCS guidelines) • Consider and treat concomitant depression, anxiety, agitated delirium, nocturia, and sleep apnoea	• Attention to sleep hygiene
Other	Pain	• As per World Health Organization ladder (avoid non-steroidal anti-inflammatory drugs) • Opioids	• Physical therapy • Occupational therapy • Massage

CCS, Canadian Cardiovascular Society; HF, heart failure.

HF symptoms

GI symptoms

CNS symptoms

Other - Pain

Palliative Approaches in Advanced Heart Disease

- De-prescribing and aligning medications with goals
- Preventing Avoidable Readmissions
- Collaboration with cardiology for shared decision-making

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Acetazolamide in Acute Decompensated Heart Failure with Volume Overload

W. Mullens, J. Dauw, P. Martens, F.H. Verbrugge, P. Nijst, E. Meekers, K. Tartaglia, F. Chenot, S. Moubayed, R. Dierckx, P. Blouard, P. Troisfontaines, D. Derthoo, W. Smolders, L. Bruckers, W. Droogne, J.M. Ter Maaten, K. Damman, J. Lassus, A. Mebazaa, G. Filippatos, F. Ruschitzka, and M. Dupont, for the ADVOR Study Group*

ABSTRACT

BACKGROUND

Whether acetazolamide, a carbonic anhydrase inhibitor that reduces proximal tubular sodium reabsorption, can improve the efficiency of loop diuretics, potentially leading to more and faster decongestion in patients with acute decompensated heart failure with volume overload, is unclear.

METHODS

In this multicenter, parallel-group, double-blind, randomized, placebo-controlled trial, we assigned patients with acute decompensated heart failure, clinical signs of volume overload (i.e., edema, pleural effusion, or ascites), and an N-terminal pro–B-type natriuretic peptide level of more than 1000 pg per milliliter or a B-type natriuretic peptide level of more than 250 pg per milliliter to receive either intravenous acetazolamide (500 mg once daily) or placebo added to standardized intravenous loop diuretics (at a dose equivalent to twice the oral maintenance dose). Randomization was stratified according to the left ventricular ejection fraction (≤40% or >40%). The primary end point was successful decongestion, defined as the absence of signs of volume overload, within 3 days after randomization and without an indication for escalation of decongestive therapy. Secondary end points included a composite of death from any cause or rehospitalization for heart failure during 3 months of follow-up. Safety was also assessed.

RESULTS

A total of 519 patients underwent randomization. Successful decongestion occurred in 108 of 256 patients (42.2%) in the acetazolamide group and in 79 of 259 (30.5%) in the placebo group (risk ratio, 1.46; 95% confidence interval [CI], 1.17 to 1.82; P<0.001). Death from any cause or rehospitalization for heart failure occurred in 76 of 256 patients (29.7%) in the acetazolamide group and in 72 of 259 patients (27.8%) in the placebo group (hazard ratio, 1.07; 95% CI, 0.78 to 1.48). Acetazolamide treatment was associated with higher cumulative urine output and natriuresis, findings consistent with better diuretic efficiency. The incidence of worsening kidney function, hypokalemia, hypotension, and adverse events was similar in the two groups.

CONCLUSIONS

The addition of acetazolamide to loop diuretic therapy in patients with acute decompensated heart failure resulted in a greater incidence of successful decongestion. (Funded by the Belgian Health Care Knowledge Center; ADVOR ClinicalTrials.gov number, NCT03505788.)

The authors' full names, academic degrees, and affiliations are listed in the Appendix. Dr. Mullens can be contacted at wilfried.mullens@zol.be or at Ziekenhuis Oost-Limburg, Schiepse Bos 6, Genk 3600, Belgium.

*A list of the principal investigators in the ADVOR Study Group is provided in the Supplementary Appendix, available at NEJM.org.

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DOI: 10.1056/NEJMoa2203094

Acetazolamide in Acute Decompensated Heart Failure (ADVOR Trial)

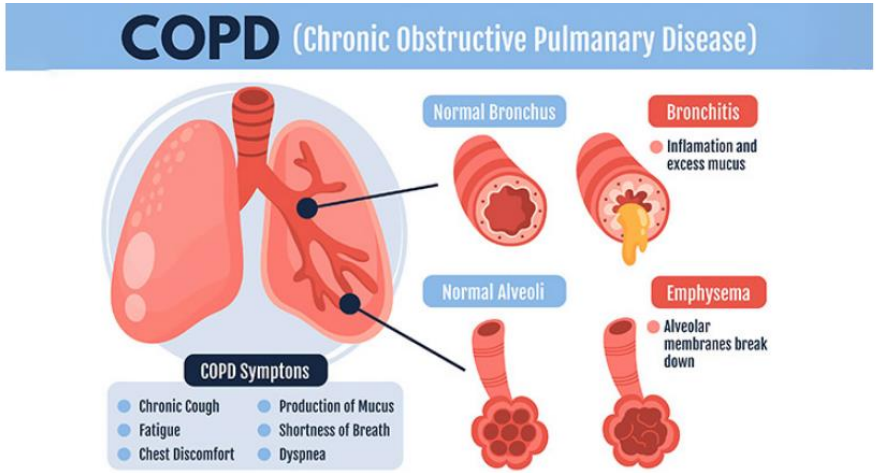
RCT, n=519: **IV acetazolamide (500 mg) vs. placebo + IV loop diuretic**

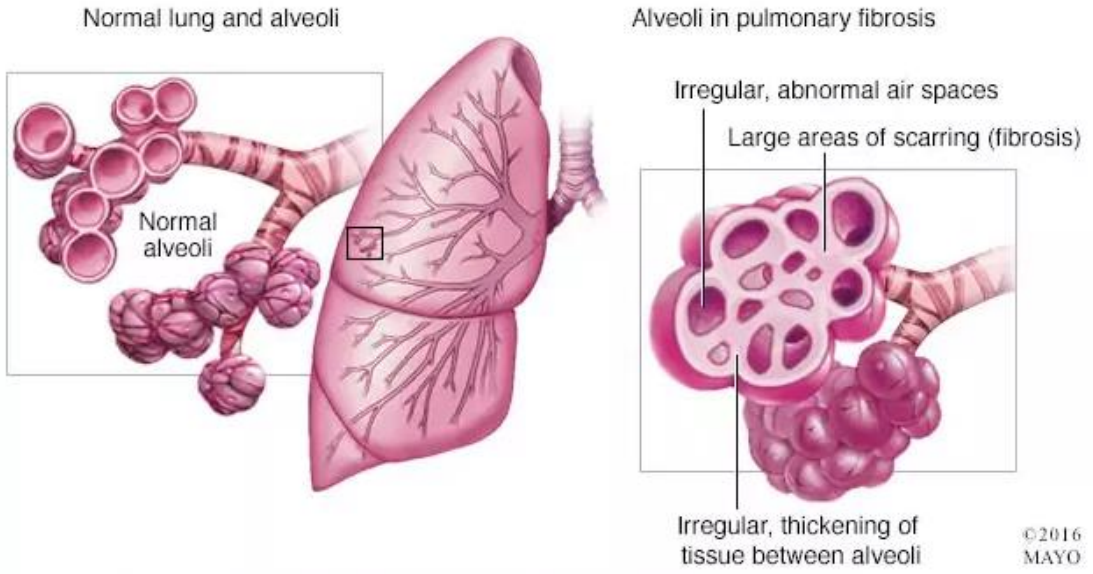
Primary outcome: **Greater successful decongestion at 3 days** (42.2% vs. 30.5%, p<0.001)

Conclusion: *Acetazolamide improved diuretic efficiency and decongestion without increased adverse effects*

Palliative Approaches in Advanced Lung Disease

- COPD
- ILD
  - Asthma/COPD syndrom
  - Pulmonary hypertension
  - CF
  - Bronchiectasis
  - Sarcoidosis





Burden of COPD in Canada

- Affects over 2 million Canadians
- Leading cause of hospital admissions for chronic illness in adults over 65
- 3rd leading cause of death in Canada
- High rates of readmissions and emergency department visits
- Significant impact on quality of life, with symptoms such as chronic cough, dyspnea, and fatigue
- Strong association with comorbidities: heart disease, anxiety/depression, and frailty
- Patients experience a progressive and unpredictable disease trajectory

CTS, ATS and GOLD guidelines

Staging COPD Based on FEV1

Severity of Airflow Limitation in COPD:

In pts w/ post-bronchodilator $FEV_1/FVC < 0.70$:

- Mild: $FEV_1 \geq 80\%$ predicted
- Moderate: $50\% \leq FEV_1 < 80\%$ predicted
- Severe $30\% \leq FEV_1 < 50\%$ predicted
- Very Severe: $FEV_1 < 30\%$ predicted

n 35% of the predicted value represents severe disease; 25% of these patients will die within two years and 55%

& Kamal, A. (2015, April). Prognosis in end-stage COPD (Fast Fact #141). Palliative Care Network of Wisconsin. https://www.mypcnow.org/fast-fact/prognosis-in-

The modified Medical Research Council (mMRC) dyspnoea scale

Grade	Description of Breathlessness
0	I only get breathless with strenuous exercise.
1	I get short of breath when hurrying on level ground or walking up a slight hill.
2	On level ground, I walk slower than people of the same age because of breathlessness, or have to stop for breath when walking at my own pace.
3	I stop for breath after walking about 100 yards or after a few minutes on level ground.
4	I am too breathless to leave the house or I am breathless when dressing.

2: MMRC Dyspnea Scale

COPD Assessment Test (CAT)

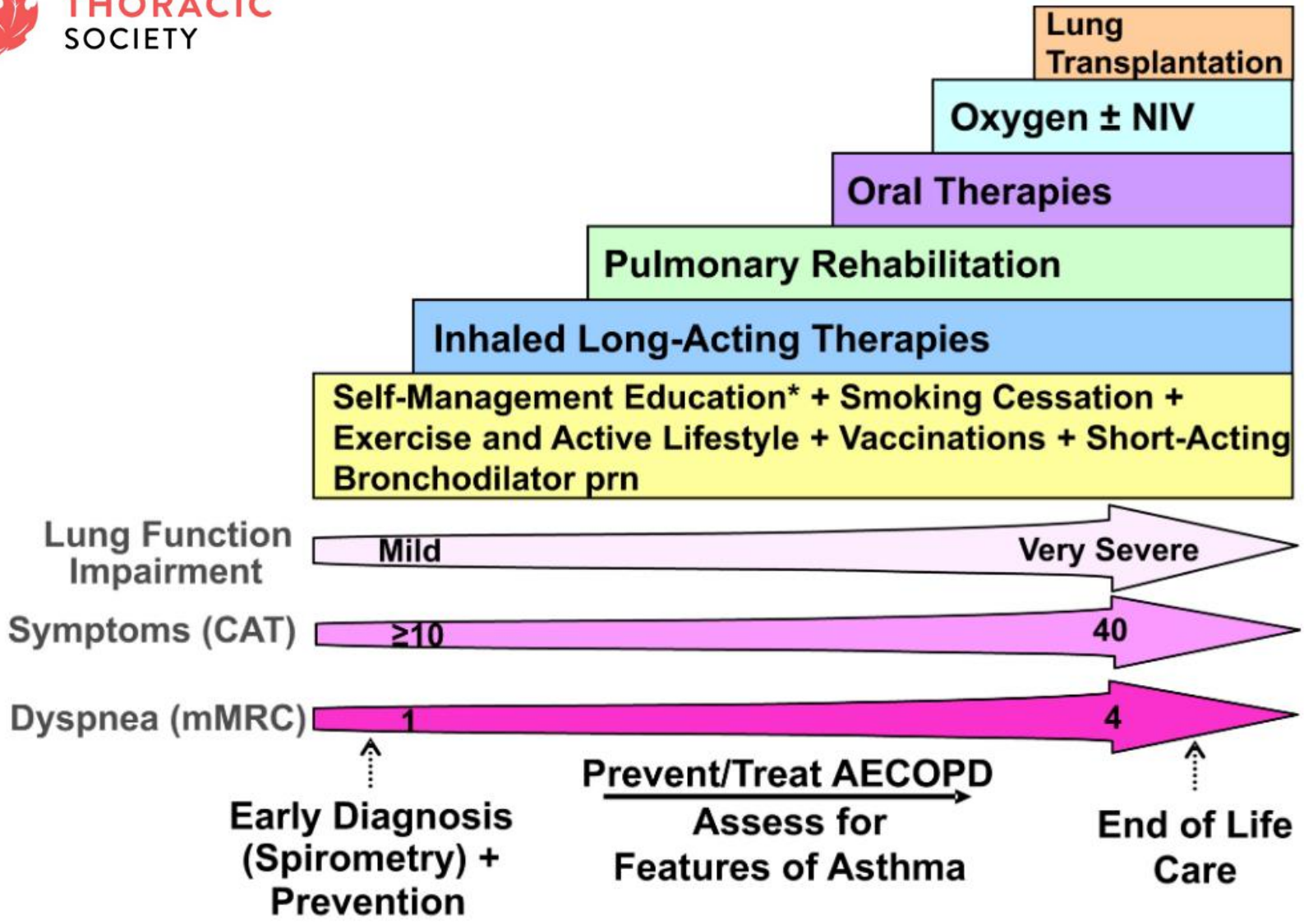
		SCORE
I never cough	0 1 2 3 4 5	I cough all the time
I have no phlegm (mucus) in my chest at all	0 1 2 3 4 5	My chest is completely full of phlegm (mucus)
My chest does not feel tight at all	0 1 2 3 4 5	My chest feels very tight
When I walk up a hill or one flight of stairs I am not breathless	0 1 2 3 4 5	When I walk up a hill or one flight of stairs I am very breathless
I am not limited doing any activities at home	0 1 2 3 4 5	I am very limited doing activities at home
I am confident leaving my home despite my condition	0 1 2 3 4 5	I am not at all confident leaving my home because of my lung condition
I sleep soundly	0 1 2 3 4 5	I don't sleep soundly because of my lung condition
I have lots of energy	0 1 2 3 4 5	I have no energy at all
		TOTAL SCORE

CAT
COPD Assessment Test

www.catestonline.org

Score	Impact	Meaning
0–9	Low	You may not experience many COPD symptoms, or at least not severe enough to affect your daily activities. Most days are good, but you cough regularly and get tired easily.
10–20	Medium	COPD symptoms affect your life regularly. You have some good days, but you get breathless easily and cough up phlegm regularly. You have 1 or 2 exacerbations each year.
21–30	High	Your symptoms regularly prevent you from doing things you want to do. Regular day-to-day activities like getting dressed are tiring. You don't feel in control of your chest problem.
31–40	Very high	You never have any good days. It takes you a long time to complete even the simplest tasks. You feel like you can't even leave the house.

CANADIAN THORACIC SOCIETY



Management Goals in COPD

1. Slow the progression of disease
2. Reduce the symptom burden associated with disease
3. Reduce exacerbations and hospitalizations
4. Improve overall survival

BODE Index:
Predicting Mortality in COPD

Body Mass Index (BMI)
- Reflects nutritional status based on weight and height

Airflow Obstruction
- Measured by FEV_1 – indicates severity of lung function impairment

Dyspnea
- Subjective breathlessness
- Assessed using tools like the mMRC Dyspnea Scale

Exercise Capacity
- Measured by the 6-Minute Walk Test
- Reflects functional status and endurance

BODE	0	1	2	3
FEV1% pred	≥65	50-64	36-49	≤35
6MWD (m)	≥350	250-349	150-249	≤149
mMRC	0-1	2	3	4
BMI ($kg.m^{-2}$)	≥21	<21		

BODE 0: 1 - 2 points; BODE 1: 2 - 4 points; BODE 2: 4 - 7 points; BODE 3: 7 - 10 points

Scoring:

Total score ranges from 0 to 10

Higher scores indicate greater risk

Mortality Estimates:

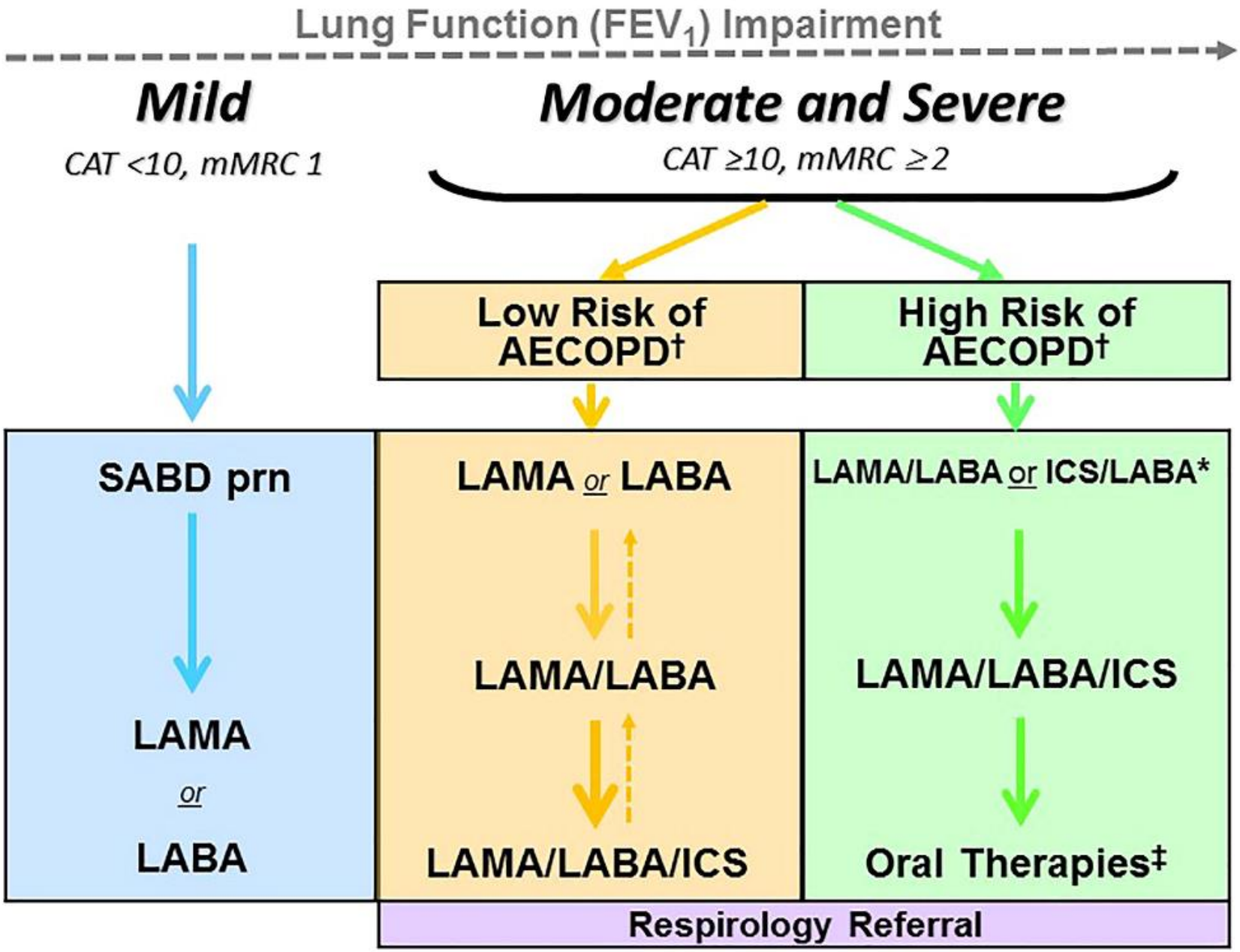
BODE Score	12-Month Mortality	24-Month Mortality	52-Month Mortality
0–2	~5%	~10%	~20%
3–4	~10%	~20%	~40%
5–6	~15%	~30%	~60%
7–10	~30%	~50%	~80%

ruction, Dyspnea, and Exercise Capacity Index in Chronic Obstructive Pulmonary Disease. New England Journal of Medicine, 35

GOLD 2023: Initial Pharmacologic Treatment Chart

Group	Symptoms	Exacerbation Risk	Recommended Treatment
A	Low (mMRC 0–1 or CAT < 10)	0–1 moderate, no hospitalizations	LAMA **or** LABA
B	High (mMRC ≥2 or CAT ≥10)	0–1 moderate, no hospitalizations	LAMA + LABA
E	Any	≥2 moderate **or** ≥1 hospitalization	LAMA + LABA ± ICS *(if eosinophils ≥300/μL)*

CANADIAN THORACIC SOCIETY



Bronchodilator & Steroid Examples

LAMA (Long-Acting Muscarinic Antagonist):

Tiotropium (Spiriva)

Aclidinium (Tudorza Genuair)

Glycopyrronium (Seebri)

Umeclidinium (Incruse Ellipta)

LABA (Long-Acting Beta2-Agonist):

Salmeterol (Serevent)

Formoterol (Foradil, Oxeze)

Indacaterol (Onbrez)

Olodaterol (Striverdi Respimat)

Vilanterol (only available in combo products)

ICS (Inhaled Corticosteroid):

Fluticasone (Flovent, in Breo Ellipta)

Budesonide (Pulmicort, in Symbicort)

Beclomethasone (Qvar)

Mometasone (Asmanex)

Combo Products (LAMA/LABA or LABA/ICS or triple):

LAMA/LABA:
Umeclidinium/Vilanterol (Anoro Ellipta)
Tiotropium/Olodaterol (Inspiolto Respimat)

LABA/ICS:
Formoterol/Budesonide (Symbicort)
Vilanterol/Fluticasone (Breo Ellipta)

Triple therapy (LAMA/LABA/ICS):
Fluticasone/Umeclidinium/Vilanterol (Trelegy Ellipta)

Oral Therapies for COPD

1. Roflumilast (Daliresp)
- PDE-4 inhibitor – reduces inflammation
- Indicated in severe COPD with chronic bronchitis and frequent exacerbations
- Helps reduce exacerbation frequency
- Common side effects: weight loss, nausea, diarrhea, insomnia

2. Azithromycin (Macrolide Antibiotic)
- Anti-inflammatory effect beyond infection control
- Consider in former smokers with frequent exacerbations
- Typically 250 mg daily or 500 mg three times per week
- **Watch for hearing loss and QT prolongation**

3. Theophylline (Methylxanthine)
- Weak bronchodilator, limited use due to narrow therapeutic window
- May be considered if symptoms persist despite maximal inhaler therapy
- Monitor for **toxicity**: tremor, arrhythmias, nausea

4. Systemic Corticosteroids
- Short courses only (e.g., prednisone 30–40 mg/day for 5 days during exacerbation)
- Avoid chronic use due to risk of osteoporosis, glucose intolerance, and infections

Interstitial Lung Disease (ILD) & Idiopathic Pulmonary Fibrosis (IPF)

Overview
- ILD = group of chronic lung conditions causing inflammation & fibrosis
- IPF = most common and severe form of ILD
- Progressive, irreversible scarring of lung tissue → impaired gas exchange

Disease Trajectory
- Unpredictable course – may be gradual decline, punctuated by acute exacerbations
- Median survival in IPF: 3–5 years from diagnosis

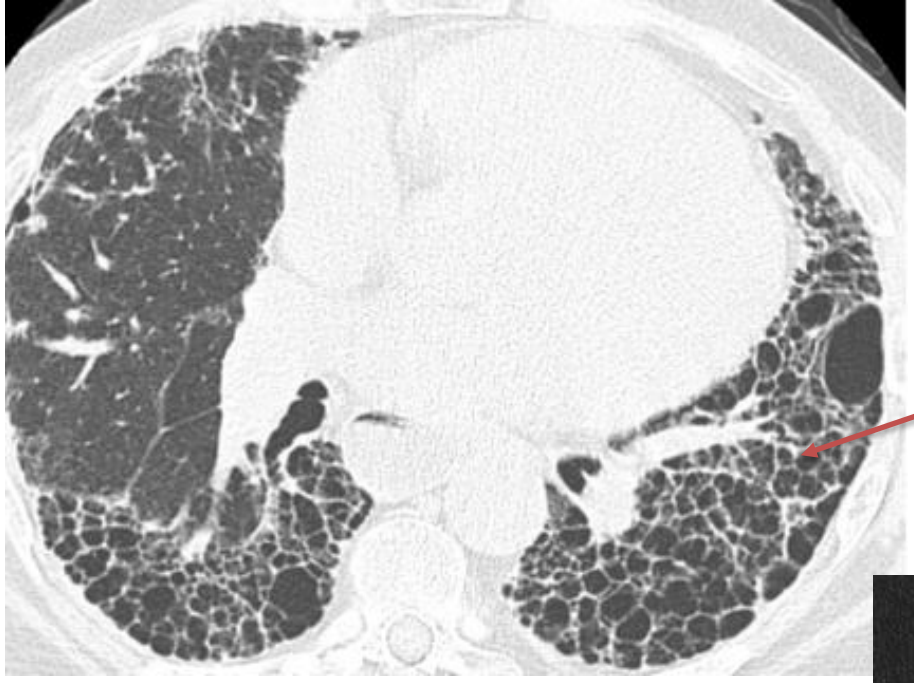
Symptoms
- Progressive dyspnea
- Chronic dry cough
- Fatigue, weight loss, psychosocial
- Oxygen desaturation on exertion and at rest**

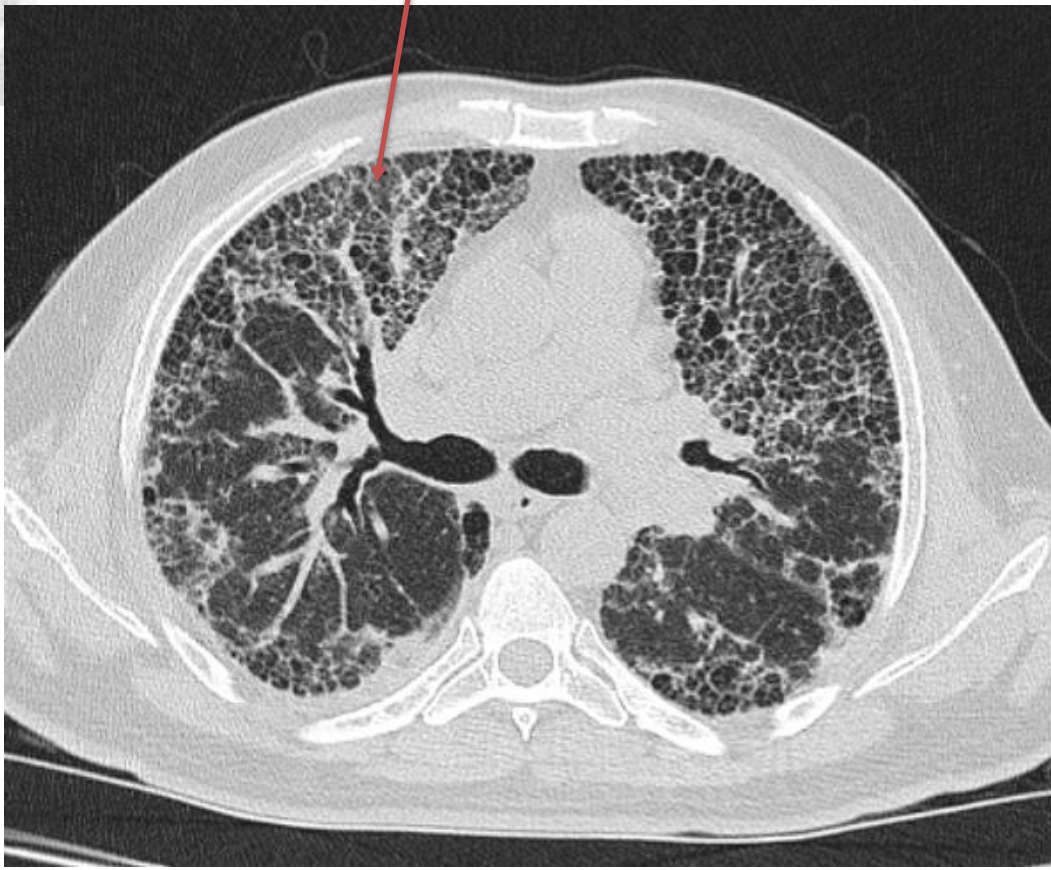
💊 Treatment Options

- Anti-fibrotics (e.g., pirfenidone, nintedanib) – slow progression, not curative
- Oxygen therapy
- Pulmonary rehab
- Lung transplant (select patients)

🧘 Palliative Approach

- Early symptom management for dyspnea, cough, anxiety
- Home oxygen, low-dose opioids, and emotional support play a central role





UIP Pattern in IPF

Reticular changes: Fine, net-like interstitial markings

Subpleural and basal predominance: Most pronounced near the lung bases and outer edges

Honeycombing: Clustered cystic airspaces, often stacked, indicating advanced fibrosis

Palliative Care in Advanced Pulmonary Disease

Breathlessness Management

- Low-dose opioids (e.g., Morphine 2.5–5 mg PO or 0.5–1 mg SC) can significantly reduce dyspnea
- Evidence supports opioid use even in non-cancer breathlessness—safe and effective when titrated carefully

Home Oxygen Therapy

- Beneficial for patients with documented hypoxemia (SpO_2 <88% or $PaO_2 \leq 55$ mmHg)
- Also considered for symptom relief in select normoxic patients with refractory dyspnea (after assessing risks/benefits)

😰 Anxiety & Panic Symptom Relief

- Dyspnea often triggers anxiety, which worsens breathlessness
- Anxiolytics (e.g., low-dose lorazepam) used cautiously
- **Non-pharmacologic strategies:**

– Pursed-lip breathing
– Fan therapy, cool environments
– Relaxation techniques and mindfulness
– Psychosocial support or counselling

🔄 Energy Conservation & Occupational Therapy

- Teach pacing, prioritizing, and modifying tasks
- Adaptive devices and home modifications (e.g., shower chairs, grab bars) improve function and safety

📋 Advance Care Planning & GOC

- Essential due to the unpredictable disease trajectory
- Advance care planning due to risk of sudden decline or exacerbation
- Revisit goals after exacerbations or hospitalizations
- Focus on aligning care with patient values (quality of life vs. life extension)

Psychosocial Support in COPD and ILD

Common Psychosocial Challenges

- Anxiety and depression (often underrecognized)
- Loss of identity and independence
- Feelings of guilt or being a burden
- Caregiver stress and burnout
- Existential distress near end of life

Supportive Strategies

- Early integration of palliative care
- Access to counselling and psychological support
- Peer support groups (e.g., pulmonary rehab)
- Spiritual care and existential support
- Educating patients and families about the illness to reduce fear of the unknown

CALM Therapy

Managing Cancer and Living Meaningfully

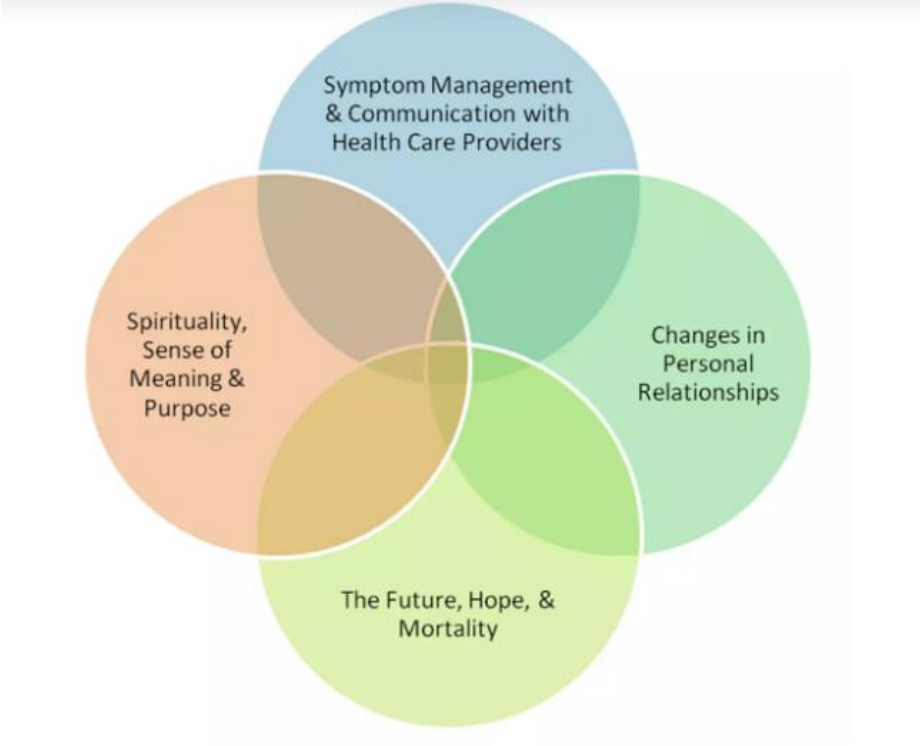
(Applied to COPD, ILD, HF & other serious illnesses)

What It Is:

A brief, evidence-based psychotherapeutic approach designed to support patients facing life-limiting illness

Why It Matters:

- Validated in advanced illness
- Helps reduce distress, anxiety, and depression
- Supports emotional processing, dignity, and autonomy



Palliative Approaches in Advanced Renal Disease

- Conservative management vs dialysis
- Symptom control in uremia
- Multidisciplinary care planning

Burden of Advanced Renal Disease in Canada

Prevalence & Demographics

- Over 4 million Canadians live with chronic kidney disease (CKD)
- Nearly 50,000 on dialysis; thousands more with stage 5 CKD not on dialysis
- Aging population + diabetes & hypertension = rising rates

System Impact

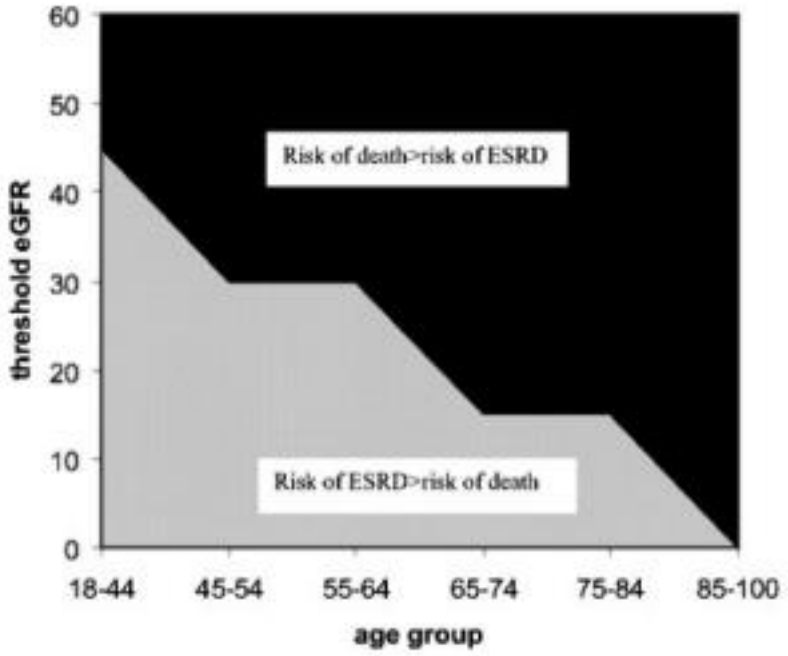
- Advanced CKD is associated with high hospitalization and readmission rates
- One of the most resource-intensive chronic conditions in Canada
- Dialysis care accounts for a major portion of provincial healthcare budgets

Patient Impact

- High symptom burden: fatigue, pruritus, pain, nausea, sleep disturbances
- Significant impact on quality of life and functional independence
- Patients often face complex decisions about dialysis initiation and withdrawal
- High prevalence of depression and caregiver stress

Stages	GFR value ml/ min/1.73m2	Classification
I	>90	Normal or High
II	60-89	Slightly decreased
III A	45-59	Mild to moderately decreased
III B	30-44	Moderately to severely de-creased
IV	15-29	Severely decreased
V	<15	Kidney failure

Relationship between age, eGFR, and risk of death in relation to risk of ESKD



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💭 To Dialyze or Not to Dialyze?

When is Dialysis Considered?

1. Typically considered when eGFR <10

2. Especially when patients develop complications of kidney failure, such as:

- Volume overload
- Electrolyte disturbances
- Uremic symptoms (e.g., encephalopathy, pericarditis)

Who May Not Benefit from Dialysis?

Evidence from observational and retrospective studies suggests limited benefit in the following populations:

- Patients >70 years with poor functional status
- Patients >75 years with ischemic heart disease or cognitive impairment
- Patients >80 years

– Living in nursing homes

– Experiencing functional decline around dialysis initiation

Chronic Renal Failure: What Symptoms to Expect

1 Fluid Overload

- Can occur at any stage of renal failure
- Caused when sodium intake exceeds the kidney's excretory capacity
- Leads to edema, pleural effusions, and pulmonary edema

→ Patients may present with dyspnea, orthopnea, and weight gain

2 Mineral Bone Disease / Electrolyte Imbalance

- Begins early, often when eGFR < 60
- Elevated phosphate and PTH levels contribute to:

→ Pruritus, vascular calcification, bone pain, and secondary hyperparathyroidism

3 Anemia of Chronic Kidney Disease

- Typically presents when eGFR < 30, but can occur earlier in:

→ Patients with diabetes, inflammatory conditions, or iron deficiency

- Symptoms include fatigue, pallor, reduced exercise tolerance

4 Uremic Toxin Accumulation

- Most common when eGFR < 10
- Accumulation of unmeasured metabolic waste products leads to:

→ Nausea, anorexia, itching, cognitive changes, and encephalopathy

→ Severe cases may develop pericarditis or seizures

Interventions to Slow Renal Decline

1 Optimize Blood Pressure Control

- Target: <130/80 mmHg (especially with proteinuria)
- Use ACE inhibitors or ARBs – reduce intraglomerular pressure & proteinuria

2 Control Diabetes

- Aim for HbA1c ~7% (individualized)
- Use SGLT2 inhibitors (e.g., empagliflozin, dapagliflozin) → proven renal-protective benefits

3 Lifestyle Modifications

- Low-sodium diet (<2g/day)
- Avoid NSAIDs, smoking cessation
- Moderate protein intake

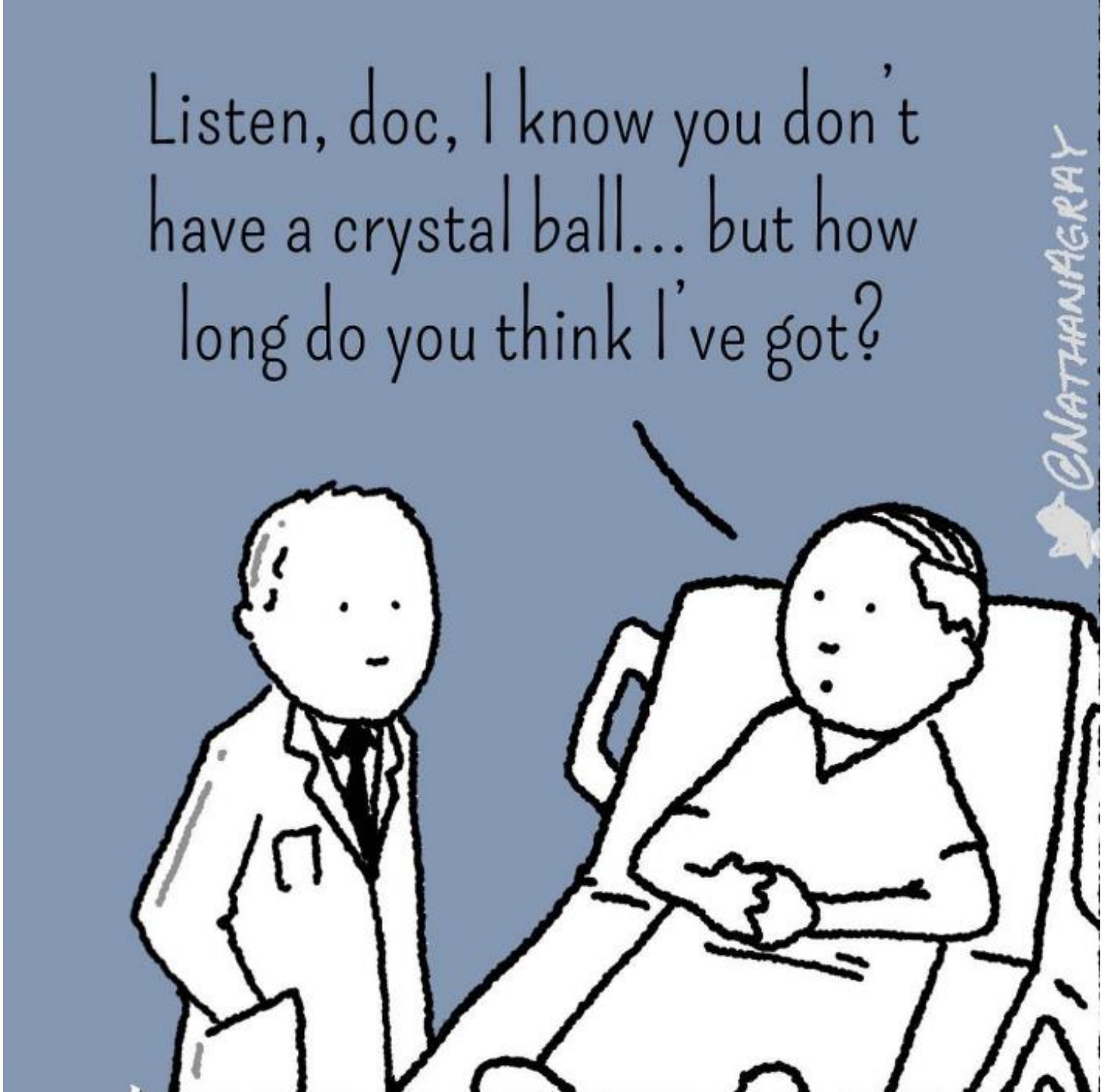
4 Treat Metabolic Complications

- Manage acidosis with sodium bicarbonate if serum bicarb <22 mmol/L
- Address anemia, hyperphosphatemia, and secondary hyperparathyroidism

5 Avoid Nephrotoxins

- Limit contrast dyes, NSAIDs, and certain antibiotics (e.g., aminoglycosides)
- Adjust drug dosing based on GFR

💬 How to Answer: “How long will I survive without dialysis?”


Listen, doc, I know you don't have a crystal ball... but how long do you think I've got?
@NATHANAGRAY


Why do people assume I don't have a crystal ball? Who told you that?


HOW DARE YOU QUESTION
MY POWERS!!!!!!

Inkvessel. (n.d.). [Title or description of the image if available] [Digital artwork]. Instagram. https://www.instagram.com/inkvessel/?hl=en

💬 How to Answer: “How long will I survive without dialysis?”

1. Acknowledge the difficulty and emotion of the question.

"*That’s a really important and difficult question. I appreciate you asking, and I want to answer it as honestly and respectfully as I can.*"

2. Frame the answer based on individual factors.

"*Survival without dialysis varies a lot from person to person. It depends on things like your overall health, how well your body can manage fluid and waste, and whether you're having any complications like high potassium or fluid overload.*"

3. Provide general estimates if appropriate.

If the patient is stable, choosing conservative management:

“Some people live months or short years with careful symptom management, especially when kidney function declines slowly.”

If the patient is acutely deteriorating or refusing dialysis in the setting of uremia, hyperkalemia, or fluid overload:

“In more advanced cases where toxins and fluid can’t be cleared, it can be a matter of short days. But we will support you every step of the way and manage symptoms as best we can.”

4. Reassure focus on quality and comfort.

"Whether or not dialysis is started, we’ll focus on keeping you comfortable, supporting your goals, and ensuring that you’re not in distress."

💊 Pain Management in Advanced Renal Failure

⚠ **Avoid Nephrotoxic Analgesics**

• NSAIDs can reduce residual kidney function and should be avoided

• Acetaminophen is the preferred first-line agent for mild to moderate pain

📌 **Adjuvant Analgesics**

• **Tricyclic antidepressants (TCAs) (e.g., amitriptyline):**

– No renal dose adjustment needed, but monitor for side effects

• **Gabapentin & Pregabalin:**

– Require renal dosing

– Often discontinued when dialysis is stopped due to accumulation risk

💉 **Opioids**

• Preferred options in renal failure:

– Methadone and Fentanyl

– No active metabolites requiring renal clearance

• Avoid morphine, hydromorphone, and codeine in later stages or post-dialysis withdrawal due to toxic metabolite buildup

Managing Symptoms After Dialysis Withdrawal: What to Expect and How to Support Patients

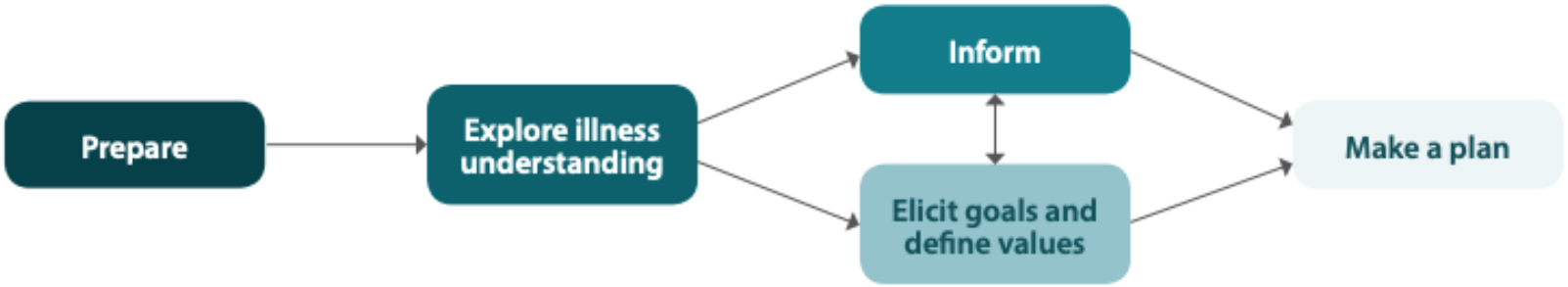
⏳ **Timeframe:**

- Most patients live for days to weeks, depending on residual kidney function, urine output, and fluid/electrolyte balance. Patients who are anuric typically survive 7–10 days after stopping dialysis.

Symptom	Why It Happens	How to Manage
Fatigue & Drowsiness	Uremia, anemia, overall decline	Reassure, encourage rest, adjust expectations
Pruritus (Itching)	Phosphate buildup, uremia	Antihistamines (e.g., hydroxyzine), gabapentin, moisturizers
Dyspnea	Fluid overload, metabolic acidosis	Low-dose **opioids** (e.g., morphine 1–2 mg SC), oxygen, **furosemide, Sodium bicarbonate**
Nausea/Vomiting	Uremia, gastroparesis - triggered chemoreceptor zone	**Haloperidol**, **metoclopramide**, **ondansetron, methotrimeprazine**
Restlessness/Delirium	Uremic encephalopathy	H**aloperidol**, **Midazolam**, **methotrimeprazine**
Pain	Bone disease, neuropathy, other chronic issues	Regular **opioid use**, titrated carefully
Anxiety/Distress	Existential fear, dyspnea	Reassurance, **opioids**, **benzodiazepines**, **psychosocial support**

Communication and Goals of Care

- Early and ongoing GOC conversations
- Addressing uncertainty
- Using frameworks like SPIKES or REMAP



1. SPIKES

Used for breaking bad news and serious conversations.

- S – Setting up the conversation
- P – Perception of illness
- I – Invitation to share information
- K – Knowledge sharing
- E – Empathy and validation
- S – Summarize and strategize

2. REMAP

For navigating serious illness conversations and aligning treatments with values.

- R – Reframe the situation
- E – Expect and respond to emotion
- M – Map out values and goals
- A – Align with patient values
- P – Propose a plan

3. Serious Illness Conversation Guide (SICG) – by Ariadne Labs, adapted in Canada

Used in many Canadian hospitals and home care settings.

Structured prompts:

- *“What are your goals if your health worsens?”*
- *“What are you hoping for? What are you most worried about?”*
- *“What trade-offs are you willing or not willing to make?”*
- *“What is your understanding of where things are with your illness?”*
- *“What are your goals if your health worsens?”*
- *“What abilities are so critical to your quality of life that you can't imagine living without them?”*
- *“If time were short, how would you want to spend it?”*
- *“How much are you willing to go through for the possibility of more time?”*

🤝 Supporting Families and Teams

😓 Caregiver Burden & Anticipatory Grief

- Recognize emotional, physical, and financial stress on caregivers
- Validate grief that begins before death (anticipatory)
- Offer respite, psychoeducation, and access to community supports

🧒💲 Interdisciplinary Collaboration

- Encourage shared decision-making across disciplines
- Regular team check-ins improve alignment and reduce moral distress
- Involve spiritual care, social work, and allied health early

⚖️ Ethical Dilemmas & Role Clarity

- Clarify roles and expectations during high-stress situations
- Support team members through ethical uncertainty (e.g., futility, withdrawal of care)
- Use debriefs and reflective practice to maintain team cohesion

Key Takeaways

- Palliative care enhances care for chronic illness
- Integration should be proactive, not reactive
- Communication and values-based care are essential

Other Non-Malignant Diseases Often Overlooked in Palliative Care

While heart failure, COPD, and CKD are commonly recognized, there are several other serious non-malignant illnesses where a palliative approach can offer significant benefit:

Neurological conditions:

Multiple Sclerosis (MS)

Amyotrophic Lateral Sclerosis (ALS)

Motor Neurone Disease

Creutzfeldt-Jakob Disease (CJD) - Subacute spongiform encephalopathy

End-stage dementia:

Particularly stages 6 and 7 on the FAST scale

Liver disease:

Especially decompensated cirrhosis with hepatic encephalopathy or ascites

Severe rheumatologic conditions:

Advanced lupus, scleroderma, or vasculitis with irreversible organ damage or frailty

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Thank You

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