Care planning and Decision Making in Frailty
Tips for clinicians

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Learning objectives

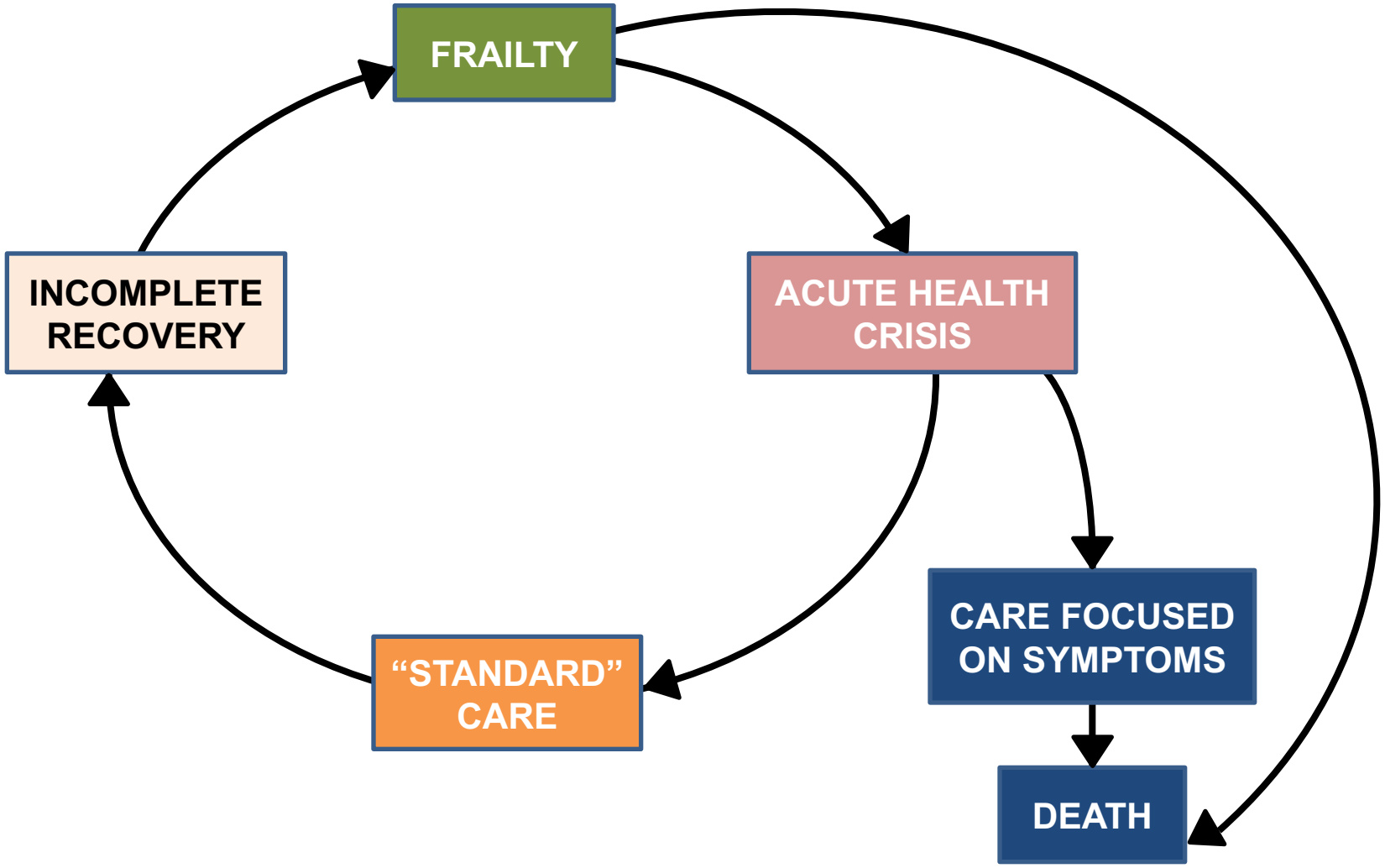
At the conclusion of this presentation, participants will be able to:

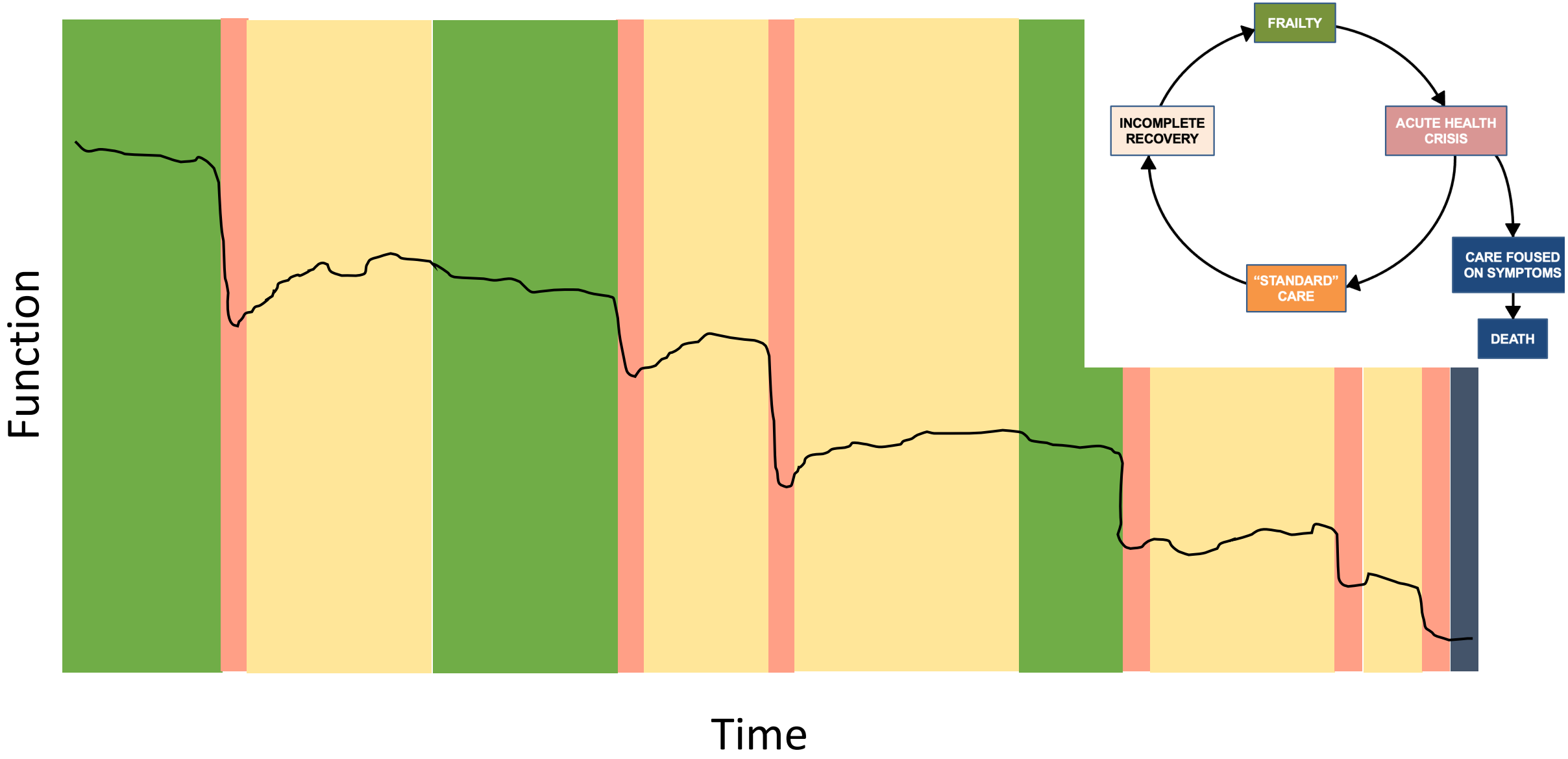
- Describe the characteristics and measurement of frailty
  Describe central challenges to optimal care in frailty
- Have an approach to care planning in frailty
- Be aware of the PATH model of care

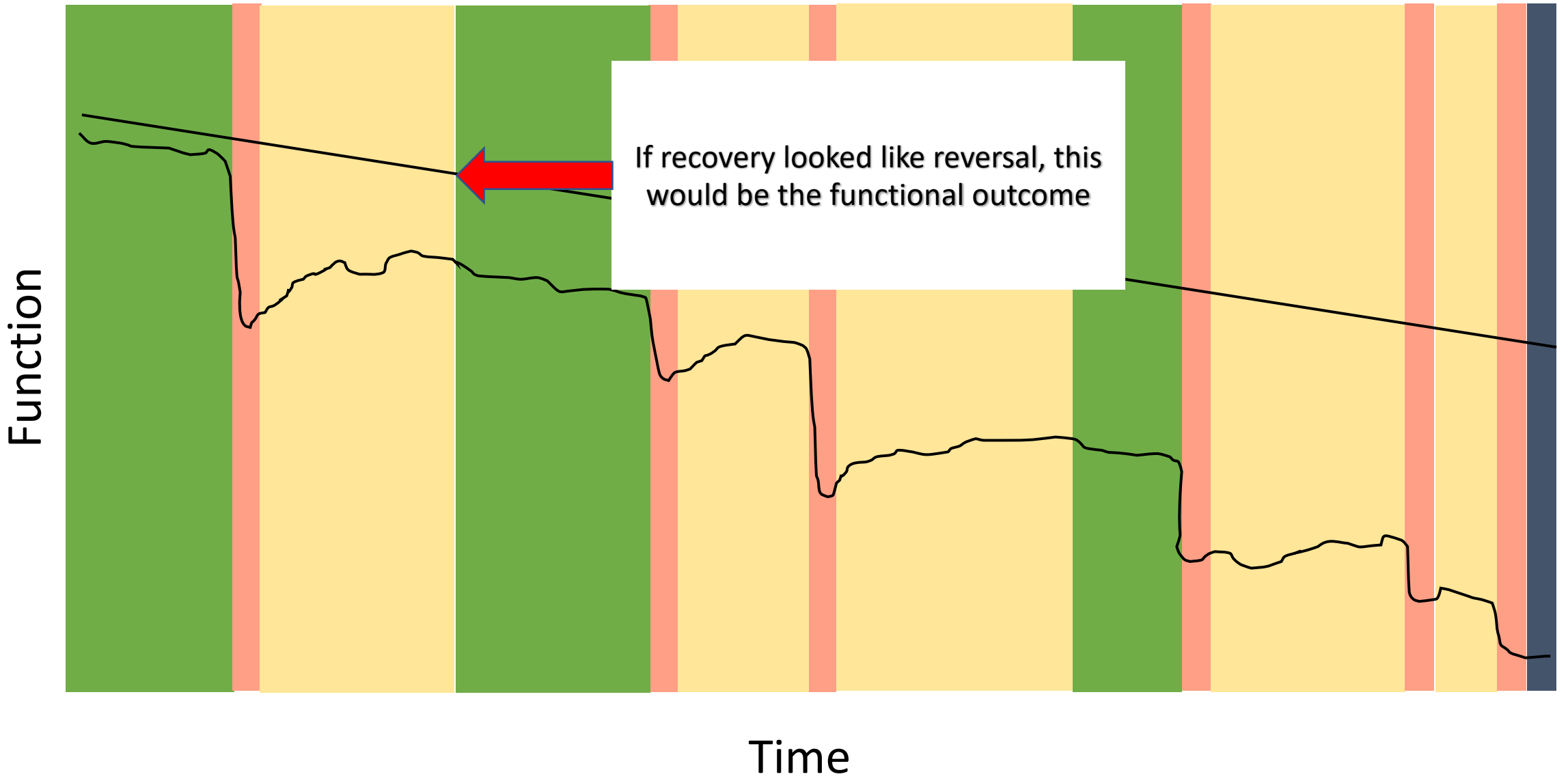
What is frailty?

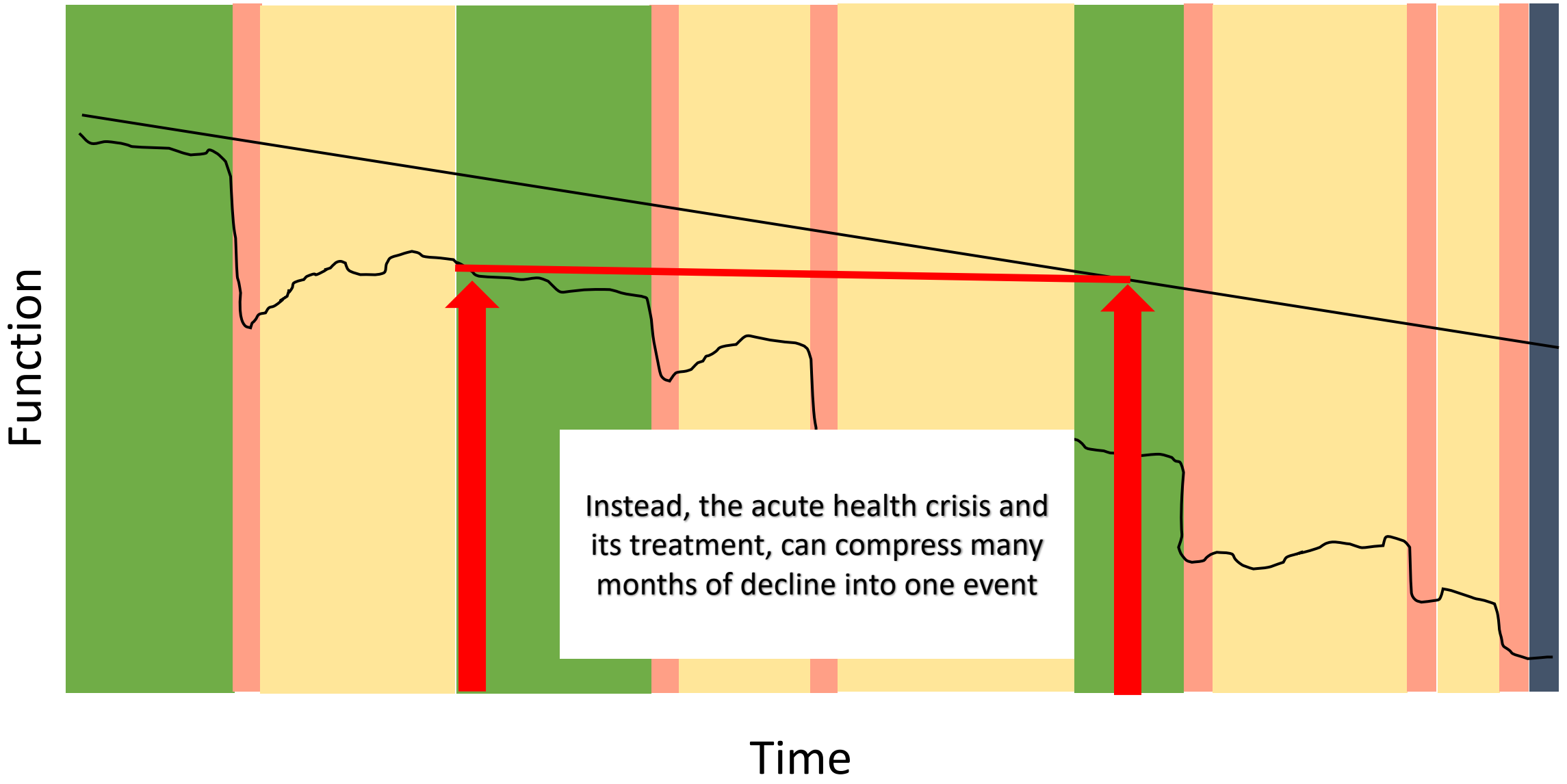
- Frailty is the baseline vulnerability due to loss of reserve capacity that results from the **accumulation of health and social stressors** over the life course
- Clinical presentations include:
  - Cognitive impairment
  - Functional decline
  - Impaired mobility

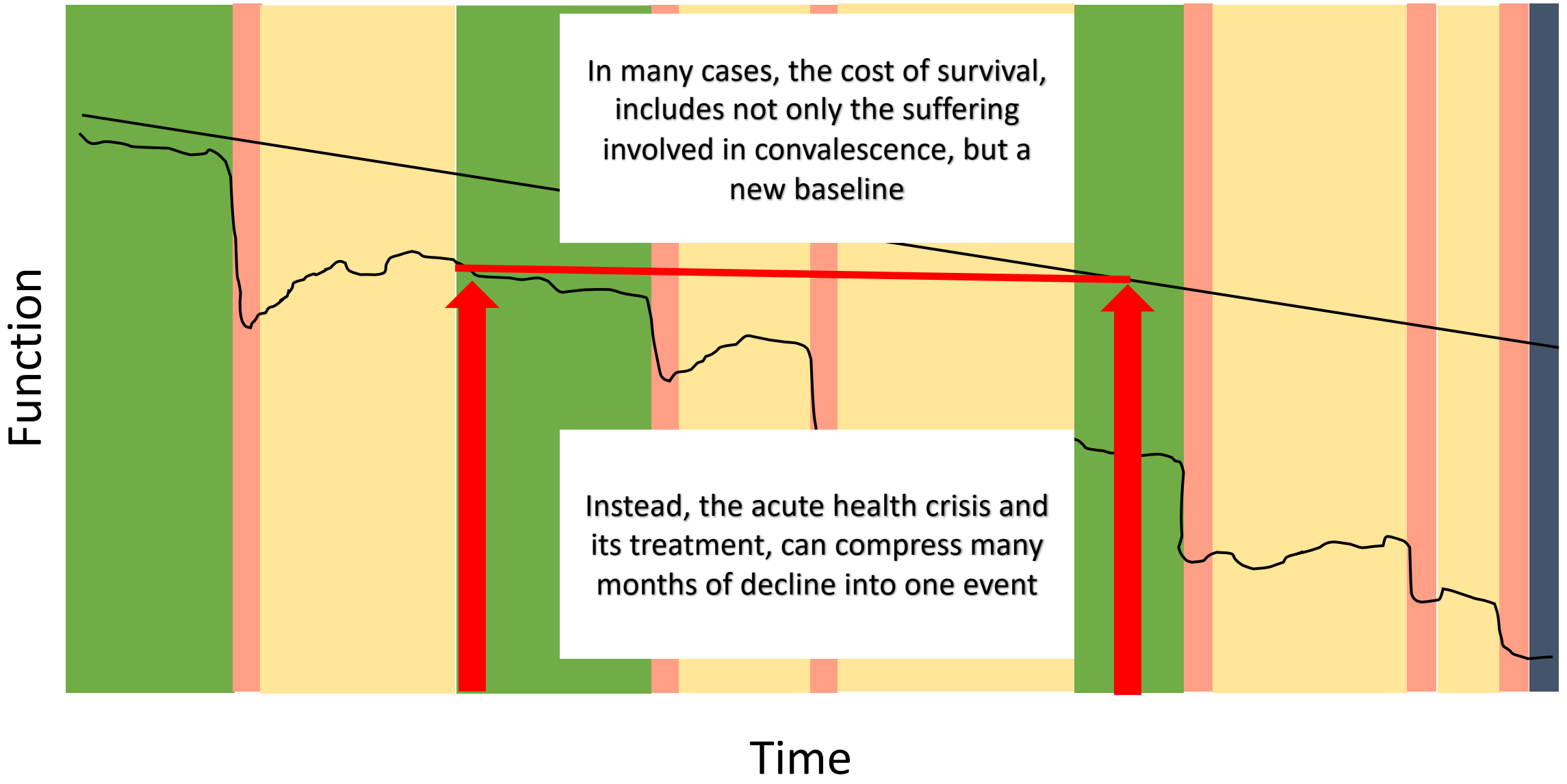
The Frailty Cycle




Function
Time
FRAILTY
ACUTE HEALTH CRISIS
CARE FOUSED ON SYMPTOMS
DEATH
"STANDARD" CARE
INCOMPLETE RECOVERY


If recovery looked like reversal, this would be the functional outcome
Function
Time


Function
Instead, the acute health crisis and its treatment, can compress many months of decline into one event
Time


In many cases, the cost of survival, includes not only the suffering involved in convalescence, but a new baseline
Instead, the acute health crisis and its treatment, can compress many months of decline into one event
Function
Time

Frailty is

- **The byproduct of optimal care**
  - The longer we live, the more health issues we accumulate
  - Frailty is part of the chronic disease management equation

Frailty is

- **A baseline characteristic**
  - We measure frailty based on the person's **usual health**, not how they look during acute illness
- **A key prognostic indicator**
  - Across populations, health conditions, interventions, and scales, frailty is associated with poor outcomes

1. Makary MA. J Am Coll Surg 2010; 210:901–908
2. Lin H-S. BMC Geriatr. 2016; 16(1): 157.
3. Vermeiren S. J Am Med Dir Assoc. 2016 Dec 1;17(12):1163.e1-1163
4. Lee DH and Hirsch GM. Circulation. 2010;121:973-978
5. Ekerstad N. Circulation 2011; 124:2397–2404
6. Rockwood K. CMAJ 2005; 173:489–495.
7. Searle SD. BMC Geriatr 2008; 8:24

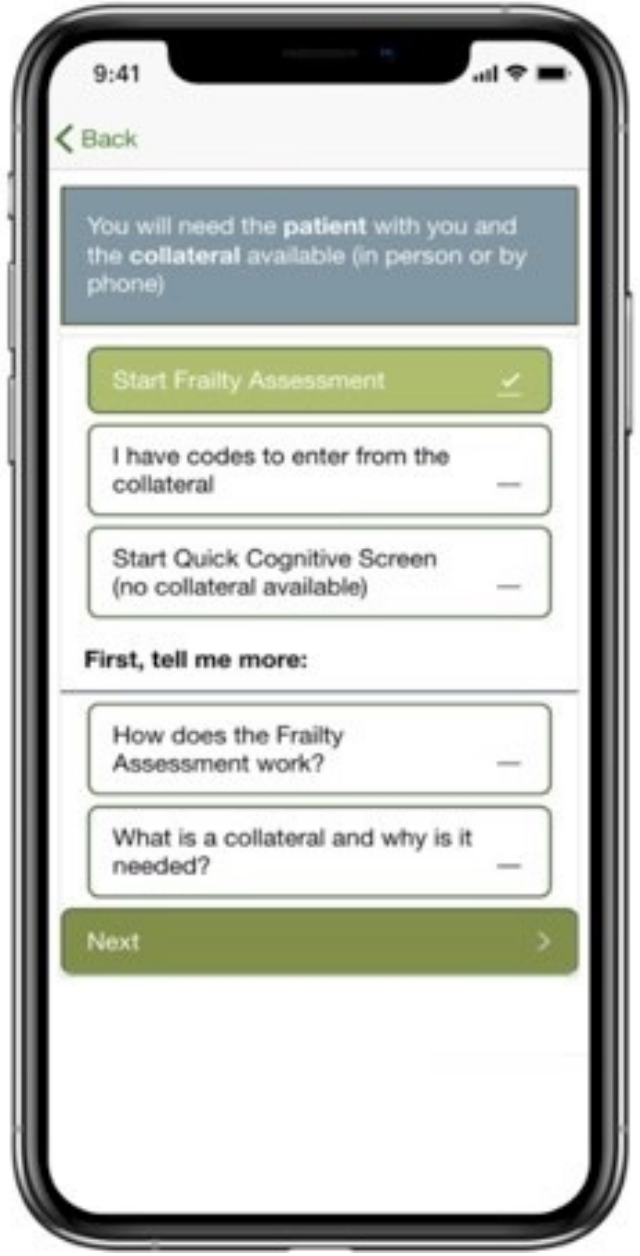
The Clinical Frailty Scale

	Level	Description
1	Very Fit	No limitations, exercise regularly
2	Well	No limitation, exercise occasionally
3	Managing Well	Don’t exercise per se, disease symptoms well-controlled
4	Vulnerable	Slowed up, symptoms from chronic disease
5	Mildly Frail	Need help with IADLs
6	Moderately Frail	Dependent for IADLs, some reminders for BADLs
7	Severely Frail	Dependent for BADLs
8	Very Severely Frail	Completely dependent upon others

Rockwood, K., Song, X., MacKnight, C., Bergman, H., Hogan, D. B., McDowell, I., et al. (2005). CMAJ, 173(5), 489-95.

The Frailty App

- Free to use (Apple/Android)
- Can be completed by collateral remotely and airdropped to your device
- Creates a mini-CGA report for the chart
- Links to frailty-level specific care guidelines



Optimal care in frailty

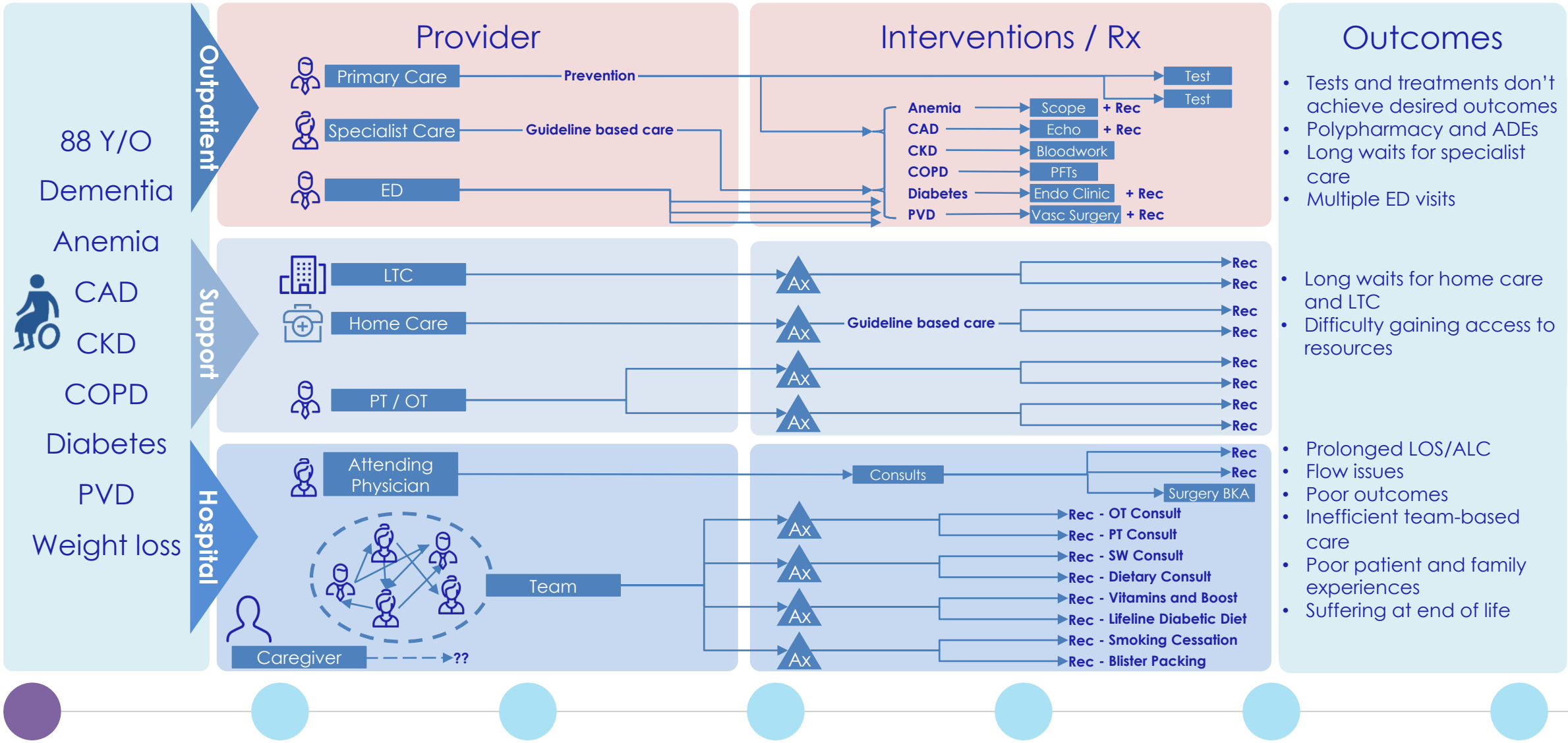
- **Holistic**: designed to maximize to overall wellbeing
- **Curated**: fewer, more meaningful (to the patient) goals
- **Tailored**: individualized
- **Intentional** : maximizing the functional lifespan/squaring the trajectory of decline (if desired)

nova scotia health authority

What is holding us back?

1. Single-system disease model
2. A culture of therapeutic optimism
   - Understanding of suffering is limited to physical symptoms
3. Failure to recognize dementia as a key driver of frailty
4. Undervalue the skillset needed

Single-system care



What we *can* do vs what we *should* do

- Geriatric Medicine was created circa 1935 by Marjorie Warren to overcome ageism/nihilism
- Today, GM has honed the art of rehabilitation
  - We may have lost an appreciation of mortality along the way
  - A gap in care remains for those who are not responding
  - Moral distress abounds
- Frail older adults are systematically excluded from most RCTs
  - Suffering is not included in the cost of standard of care interventions
  - Death by a thousand guidelines

How do we communicate prognosis in non-cancer illness?

90 individuals who were likely to die over the next year according to their doctor

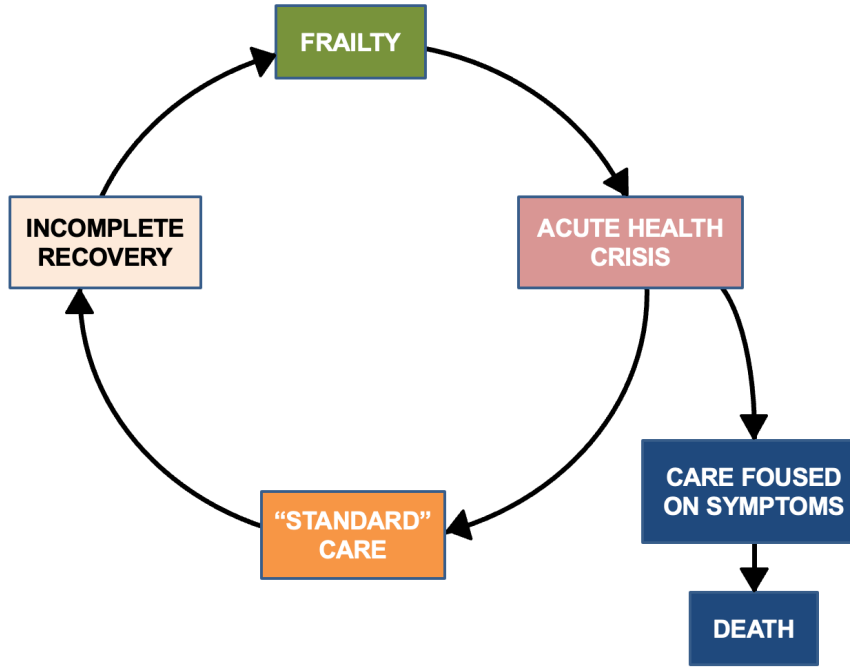
Patient aware of own life expectancy		
	Cancer, %	Heart disease, %
Yes	71	19
No	6	56
Unsure	24	25

Zapka G, *J Aging Health* 2006 Dec;18(6):791-813

Pre-Palliative Era vs Current Frailty Care	
Pre-palliative era	Current EOL care for older adults
Withholding information about diagnosis	Avoid discussions of prognosis
Lack of awareness about palliative care in cancer	• Lack of awareness of “frailty” • Lack of recognition of dying • Inattention to how people die
Comfort care withheld	Comfort care delayed
Culture of cure	• Futile treatments offered • Specialty-based mandates
Spiritual approach at odds with medical care	Insensitivity to needs of dying
No systematic approach for PC	System does not support good EOL care

Tip 1. Use the frailty cycle

- Recognize the health crisis as an opportunity to take a step back and revisit the options
- Use the frailty cycle when discussing options for care
  - What to expect from recovery
  - The suffering innate to the standard of care



Tip 2. Help others expand their appreciation of suffering

Tip 2. Help others expand their appreciation of suffering

- Suffering may be worth it if there is an expectation of recovery
  - Mini tip 3: Talk in terms of expectations
    - What do you expect to happen? (in your experience)
    - What might the functional outcomes of incomplete recovery mean?
- Without recovery, suffering may lose its meaning
- Without baseline symptoms, suffering may lose its meaning
  - Solitary pulmonary nodule, best case scenario

What is holding us back?

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4. Undervalue the skillset needed

Tip 4: Appreciate dementia as a key driver of frailty

- People with dementia are vulnerable and often respond poorly to interventional treatments[1, 2, 3, 4]
- Dementia is incurable and associated with reduced life expectancy [5, 6]
- Dementia is key to understanding the benefits of life prolonging interventions
- We tend to undervalue suffering in dementia (i.e. BPSD, delirium)
- **We commonly fail to identify dementia [7-12]**

1. Hanson, L. *JAGS 2008;56*(1), 91-98.
2. Teno, J.M., *JAMA* 2001;285:2081
3. Ferrell, B.A. *Ann Intern Med* 1995;123:681-687
4. Fukuse. Chest 2005
5. Bickel. Dementia and Geriatric Cognitive Disorders 2008
6. Fong, RF. Neurology 2009
7. Knopman DS. Am. J. Med. 1998 Apr 27;104(4A):2S–12S; 39S–42S.
8. Valcour VG Arch. Intern. Med. 2000 Oct 23;160(19):2964–8
9. Ganguli M. J Am Geriatr Soc. 2004;52:1668-75. [PMID: 15450043]
10. Holsinger T. JAMA. 2007;297:2391-404. [PMID: 17551132]
11. Chodosh J.. J Am Geriatr Soc. 2004;52:1051-9. [PMID: 15209641].
12. Querfurth HW.. N Engl J Med. 2010;362: 329-44. [PMID: 20107219]

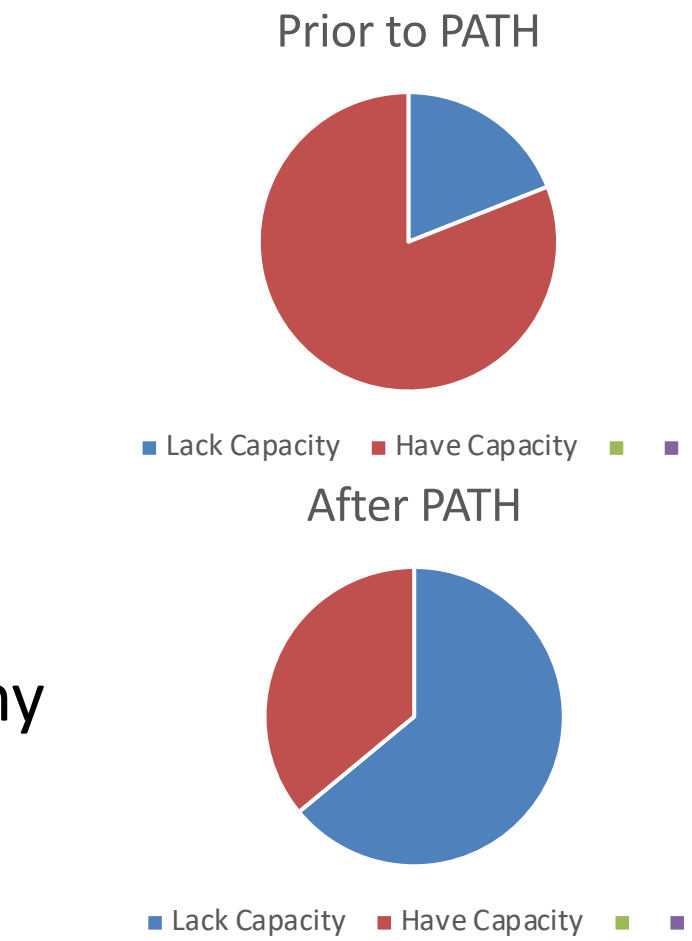
Frailty and Dementia Stage

	Frailty Level	**Dementia (FAST) stage**	
1-3	Aging as expected	Normal cognition	
4	Vulnerable	MCI	Help with high level tasks
5	Mildly Frail: need help with some IADLs	Mild	Help with some IADLs Forget current events
6	Moderately Frail	Moderate	Help with all IADLs, cuing Forget current events
7	Severely Frail: need help with all BADLs	Severe	Need help with all BADLs Forget close relatives
8	Very Severely Frail	Very Severe	Non verbal, non-ambulatory

Reisberg B. Functional assessment staging (FAST). Psychopharmacol Bull. 1988;24:653-659.
Rockwood K, Song X, MacKnight C et al. A global clinical measure of fitness and frailty in elderly people. CMAJ. 2005;173:489-495.

Tip 5: Consider the risks of assuming capacity

- In acute medicine we have reason to question capacity:
  - 1/3 of hospitalized older adults have dementia (most are undiagnosed)[1]
  - A further 1/3 have delirium[2]
  - Even those with "pre-dementia" may have difficulty with informed consent
    - Appreciate of individual risks and benefits[3]
    - Ability to imagine future self[4]
- When we assume capacity, we undermine autonomy



1. Briggs et al., *QJM*, 110,(1): 33–37, https://doi.org/10.1093/qjmed/hcw114
2. https://www.nice.org.uk/guidance/qs63/documents/delirium-briefing-paper2
3. Sternberg et al., JAGS 2000;48:1430-1434.
4. Okonkwo et al., Neurology 2008;71:1474-1480.

Goals of Care in Frailty

- Goals of care are outcome-oriented:
  - What are the patient's/ECP's priorities?
  - What level of intervention do we imagine might reasonably achieve the patient's goals?
  - Interventions are appropriately a dynamic mix of interventions aimed at cure and interventions aimed at symptom management

6 Steps to addressing GOC in frailty

1. Assemble the decision makers
2. Provide information
3. Elicit priorities
4. Determine which decisions can/should be made in advance
   - Provide recommendations
5. Have a plan for *just in time* decisions

Mr. B

- 78M with severe COPD
- Lives with his wife
- Dysphagia with recurrent aspiration pneumonia
  - 4 admission in 3 months, despite modified diet
- Admitted with PNA: NPO, ABX
  - Team considering G tube but concerned re operative risk/code status
  - Mr. B: “If it will help me live, then do it”

Step 1: Assemble the decision makers

- Problems with western medicine's concept of autonomy
  - Dichotomous approach to who is driving decision making
  - Capacity for informed decision making is overestimated
  - Unfairly absolves the clinician of the outcome[1]
    - Limiting role to presenting options creates false equivalence
    - Undervalues role of experience/recommendations
      - What if RCTs have limited applicability? (this is the case for most frail older adults)

1. Back et al., J Pall Med 2015;18:26-30

Mr. B

- PATH consult
  - Delirium and baseline mild stage dementia
  - Lacks insight into the diagnosis
- Mrs. B is identified as decision maker
  - “I want everything done”
  - Approached x 2, became angry, withdrew

The burden of decision making

- SDMs report confusion, uncertainty and guilt
  - Struggling to reconcile ACPs with current context
  - Receiving multiple conflicting messages about prognosis
  - Tolerating/accepting suffering on the implicit promise of recovery
- Can result in advocating the intervention instead of the outcome
- Absence of delirium/dementia ≠ capacity/comfort with decision making
  - Emotionality can impair executive function[1]
  - "Maladaptive coping" and withdrawal[2,3]
  - We never assess capacity of SDM ("she's not our patient!")

1. Mitchell and Phillips. Neuropsychologica 2007;45:617-629
2. Sullivan et al., Chest 2012;142:1440-1446
3. Roeland et al., 2014

Step 1: Assemble the decision makers

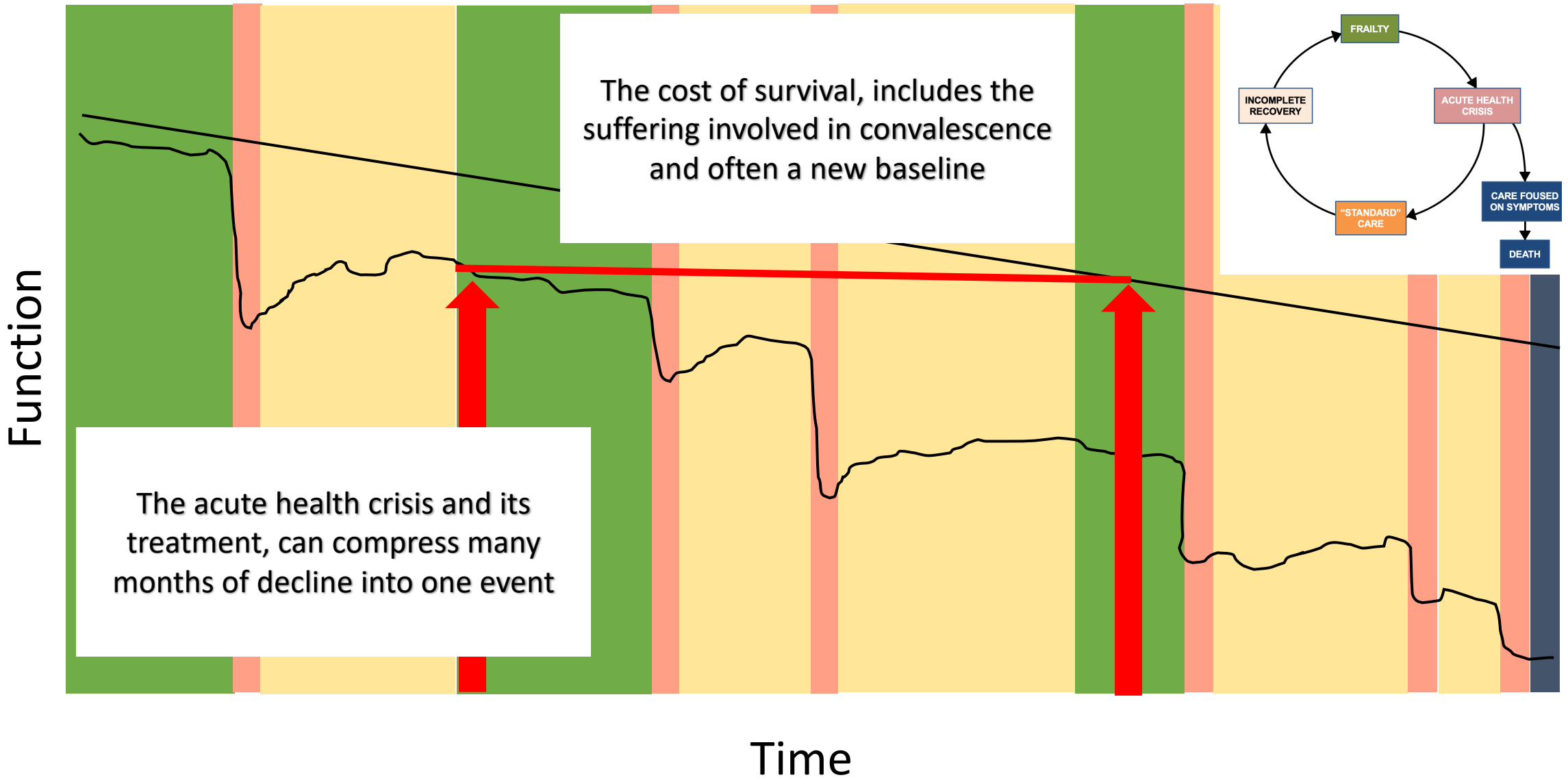
- Tips:
  - Insist on a decisional understudy
    - Resistance is an opportunity to address a gap in understanding
  - In circumstances that have the potential for high emotions/maladaptive coping
    - Request the decision maker to bring a support person
    - Brother-in-law phenomenon
  - Acknowledge the burden of the SDM role; offer support

Mr. B

- Is there someone else who could help with decision making?
- Discussion with daughter:
  - “I know they’re both terrified of death. He doesn’t want to suffer. He’d be devastated if he couldn’t go home again.”
  - “I can’t make the decision between life or death for him.”

Step 2: Provide information

- Describe disease stage and progression
- Describe dementia stage and progression
- Overlay frailty
  - Use the frailty cycle
  - Last chapter of life
  - What is certain/clarify non decisions
- Check for understanding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Step 3: Clarify priorities

- Before making recommendations, you need to understand the individual hierarchy of priorities for wellbeing:
  - Symptom control
  - Location/privacy
  - Upcoming events
  - Safety
  - Longevity
- In frailty, decisions makers must choose between priorities:
  - Ex: care designed for longevity may involve discomfort
  - Ex: Living at risk in order to be at home

Mr. B

- Discussion with daughter
- Provision of information and recommendations
  - He is in the last chapter of life (COPD, dementia)
    - These are not life or death decisions!
  - Recovery from each PNA with deliver him to a state of worsened health
  - A focus on quality of life and symptoms is appropriate
    - Priority of going home from hospital
    - No G tube
    - Morning coffee at risk for quality of life
- Brought discussion back to Mrs. B who agreed with plan

Steps to addressing GOC in frailty

1. Assemble the decision makers (with capacity)
2. Provide information
3. Elicit priorities
4. Determine which decisions can/should be made in advance
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5. Have a plan for *just in time* decisions

Mrs. P

- 75F with L THA 8 years ago
  - Infected hardware → multiple revisions, I&D
    - Chronic suppressive ABX
  - Walks with a walker, chronic pain
  - Annual visit with ortho: hardware failing → revision recommended
    - “under no circumstances am I willing to go back to the OR”
  - 2 weeks later, fall at home → L hip fracture
    - Delirium (analgesics)
    - Options: disarticulation or palliation (EOL)

Checking all the boxes

- ✓Cognitively intact, has capacity
- ✓Lived experience with OR/recovery
- ✓Informed, specific directive
  - ✓Documented, available to the team
- ✓Made 2 weeks prior to the incident

- The outcome…
- What went wrong?

Provincial Goals of Care Initiatives

- Provincial advance directive initiatives uniformly lack:
  - Assessment of capacity to make decisions
  - Involvement of the delegate for those with capacity
  - Medical context/guidance
  - Caution about making advance decisions
  - Disclosure of the limitations

"By planning in advance, you can be sure that your family, friends, and/or health care providers, know you wishes and can ensure these wishes are followed."

BC My Voice Advance Care Planning Guide

How to get the most out of ACP

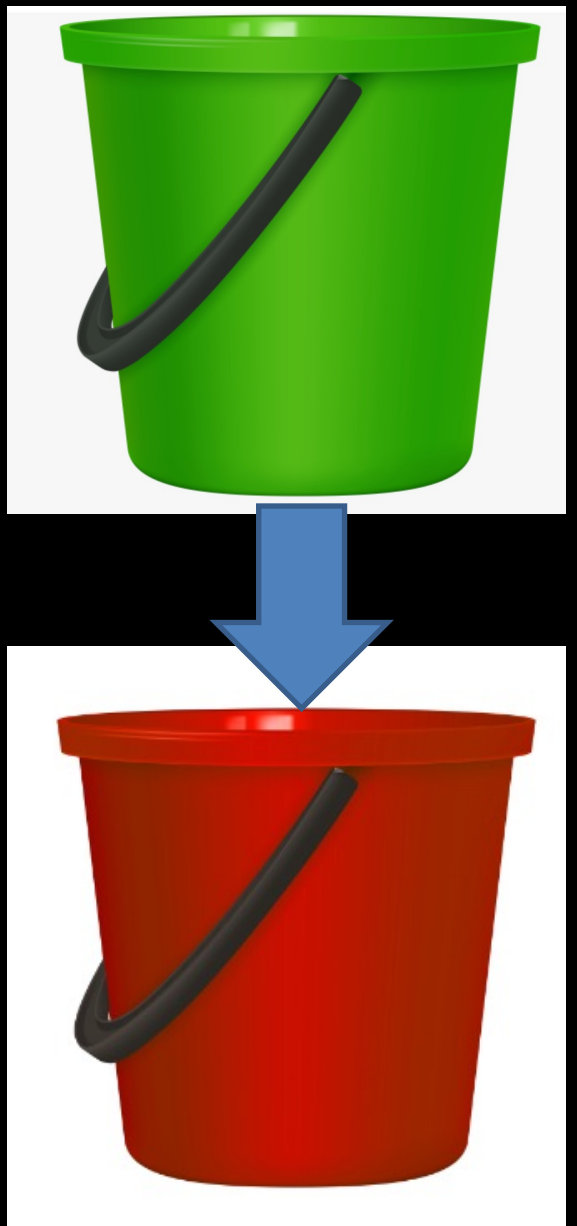
- Cognitive assessment/capacity must be routine part
- Disclose the limitations of ACP
- Use the “Bucket Approach”

How to make decisions in advance

- Red Bucket: Interventions that would not be acceptable now or in the future due to medical appropriateness/cultural/religious considerations
- Green Bucket: Everything else

How to make decisions in advance

- As frailty progresses, interventions move from the GREEN bucket to the RED bucket



How to make decisions in advance

- For healthy people, the RED bucket may be empty
- Only interventions in the RED bucket are appropriate for advance care planning decisions
- Mrs. P's stated preference would be in the green bucket

Steps to addressing GOC in frailty

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Palliative and Therapeutic Harmonization

CARE

For Patients and Family

Understand health in a more holistic way and sharpen skills for decision-making

Learn more

EDUCATION

For Learners and Trainees

Understand frailty and embrace a new model for providing care that matters

Learn more

IMPLEMENTATION

For Health Care Providers and Administrators

Sustainable care and enhanced patient outcomes

Learn more

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The Principles of PATH

1	Frailty must be at the forefront
2	Information changes medical decision making
3	Care planning should be collaborative, guided, and rigorous
4	Not all decisions should be made in advance; guidance during transitions in health is important

PATH Principles in Action

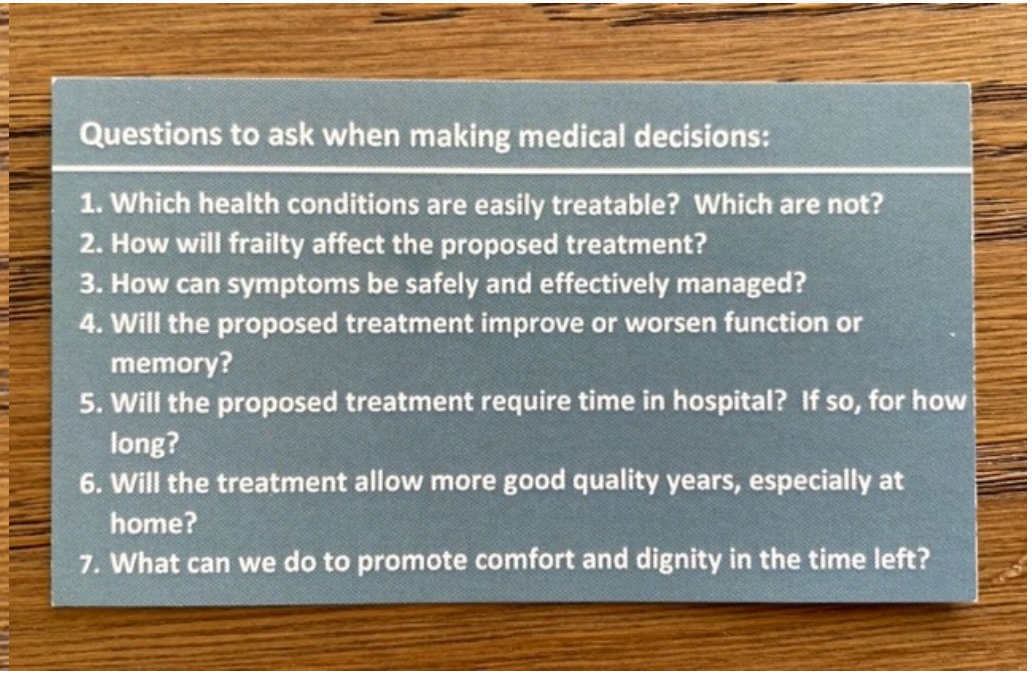
1	**Understand**	Standardized processes and tools to assemble the picture of frailty and health trajectory ***"What is this patient's story?"***
2	**Communicate**	Standardized approach to discussion of frailty and prognosis **"Did you know?"**
3	**Plan/empower**	Builds decision-maker's skills ***"What information do I need to make a decision?"***
4	**Respond**	Be available during the health crisis. ***"Who do I call and when?"***

Respond: Double-layered support for *Just in time* decisions

1. Empower decision makers with information gathering skills
2. Real-time support for the health crisis

Building skills in the decision maker

- We can’t predict the specifics of the health crisis
- The biggest challenge is missing Step 2 (Provide information)
  - Spend time with decision maker working through the following questions
  - Provide our card to the patient/decision maker



Tips for managing the health crisis

- Tip: Take a moment to prepare for the discussion
- Acknowledge your own values, and trauma
- Reflect on individualized risks/benefits before presenting options
  - Play out the best and worst case outcomes of proposed interventions
    - Example: best case in asymptomatic conditions
  - What is expected?
  - Clarify non-decisions

PATH: Referral streams

- Inpatient and outpatient settings
- Orthopedic surgery
  - Patients with severe frailty/dementia and hip fracture
  - Elective joint arthroplasty with dementia or significant frailty
    - Assessment of symptoms with dementia is important
- Cardiology/Cardiac surgery
  - TAVI (Multidisciplinary Team)
  - CABG/Open Valve Repair, PCI, AICD

PATH: Referral streams

- General surgery (hernia repair, bowel resection)
- Oncology (Radiation/chemotherapy)
- Urology (Transurethral Resection of Bladder Tumors (TURBT), Cystectomy)
- Non-cancer patients: should we transition to palliation?
- Nephrology (Dialysis)

PATH clinical outcomes

- First 855 patients completing the program:
  - 70% had decisions to make about surgery
    - 80% of these were cancelled by the patient or their family
  - 32% avoided hospitalization and were cared for at home
  - Ability to respond to health crises prevented ED visits

- High patient/family satisfaction

Moorhouse P, Mallery LH. J Am Geriatr Soc. 2012 Oct 30

Tip: Practice

- If you have a sec, could you just whip out that appendix?
- The procedural skillset required for effective care planning in frailty care is experiential
  - Takes time to practice and build
  - Not always practical on inpatient units/busy specialized medicine clinics
  - Often requires a team with similar approach and values

Conclusions

- People living with frailty are at risk of poor outcomes from standard of care procedures
- Patients and/or family value navigation for complex decisions
  - Navigation for decision-making is a specialized skill
- Avoiding unnecessary procedures can address suffering while improving appropriateness of care
- We are interested in working with anyone who wants to set up this type of program in their area

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Case: Mr. D 62M

- Decompensated cirrhosis (in setting of known EtOH liver disease) and multiple liver lesions probable HCC. INR 2.2 (Childs C)
  - No EtOH since July
  - Agitation, hallucinations, resisting care: no sign of infection/SBP
  - Started lactulose, spironolactone, bx planned
- Wife concerned re plan → CGA
  - Severely frail: dependent on wife for BADLs x 1 year, limited mobility
  - Cognitive issues at home x 2-3 years, progressive, verbal aggression
    - Significant caregiver commitment and distress
  - Jaundiced, agitated, eating candy with the wrappers still attached

Mr. D: Themes and outcome

- Standard of care is clear (and he's so *young!*)
  - We *can* but *should* we?
- Game changers:
  - New dx/understanding of baseline behaviors/cognition/frailty
  - Discussion of suffering
  - Discussion of wife's distress
  - What will further investigation/tx achieve?
- Decision to address suffering in hospital: lactulose stopped, bx canceled
  - Haldol → calm, sleeping, awake at times
  - Died 3 days after goals of care conversation