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Preparing for Serious Illness

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“Serious Illness”

A health condition carrying a high risk of mortality AND which either negatively impacts one’s daily function or quality of life OR excessively strains their caregivers.

Kelley AS et al, 2017

- ✓ **Not Necessarily Terminal**
- ✓ **May be the beginning of a long journey through the Healthcare System**



“How Should I Prepare For Serious Illness?”

Preparing for a serious illness involves several important steps that can help you and your loved ones manage the situation more effectively.

Here are some key considerations:

1. Educate Yourself

Learn about the illness, its symptoms, and treatment options.

Understand the prognosis and what to expect at different stages.

2. Financial Planning

Review insurance coverage and understand what is included.

Create a budget for potential medical expenses and other related costs.

3. Advance Directives

Prepare legal documents such as a living will and durable power of attorney for healthcare.

Discuss your wishes regarding medical treatment with loved ones.

4. Support System

Build a network of support, including family, friends, and support groups.

Consider talking to a therapist or counselor for emotional support.

5. Self-Care

Focus on maintaining physical and mental well-being through proper nutrition, exercise, and stress management techniques. Consider relaxation methods such as meditation or yoga.

6. Organize Medical Information

Keep a record of your medical history, medications, and allergies.

Have a list of healthcare providers and emergency contacts readily available.

7. Discuss Treatment Options

Have open conversations with your healthcare team about treatment plans and options.

Inquire about palliative care to manage symptoms and improve quality of life.

8. Prepare for Daily Life Changes

Consider modifications at home for comfort and accessibility.

Plan for assistance with daily activities if needed.

9. Communication

Talk openly with loved ones about your feelings and wishes.

Encourage family discussions to ensure everyone is on the same page.

10. Stay Informed

Keep up with new research or treatments related to the illness.

Attend support groups or workshops for additional insights.





Preparing for Serious Illness

1. Always be kind to and show love to your family and friends.
2. Establish and cultivate a primary care provider that you can trust.
3. Establish and cultivate a medical team that you can trust.
4. Prepare for your priorities and share them with those who will advocate for you.



When you are sick....

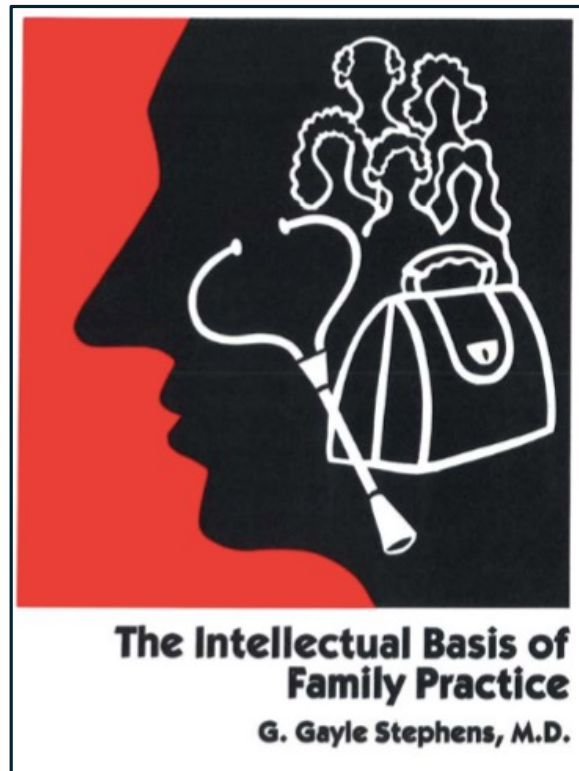
***... you need someone
who will advocate for
you.***



*Family, Friends, Animals
...be kind and live your Life Well Now!*

People die as they lived.

Family Medicine (aka. Primary Care)



“Medicine is a moral vocation that is practiced best when patients have a personal physician who can help them get what they need from the larger system in a manner that does not demean or exploit them, a personal physician who is able and willing to attend to their patients’ life experiences and individual preferences.”

How Can You Best Work with Your Primary Care Provider?

- **Let your primary care provider/team follow you!**
 - Make a routine appointment every 1-3 months to update them on your situation and allow them to catch up with you.
- Discuss your concerns about **everything**, including any physical or mental symptoms you have and your care in general. Let your team brainstorm with you!
- When needed, ask for extended visit time (e.g. schedule 40 minutes instead of the usual 20)
- Always make follow up plans.



How Can You Best Work with Your Primary Care Provider?

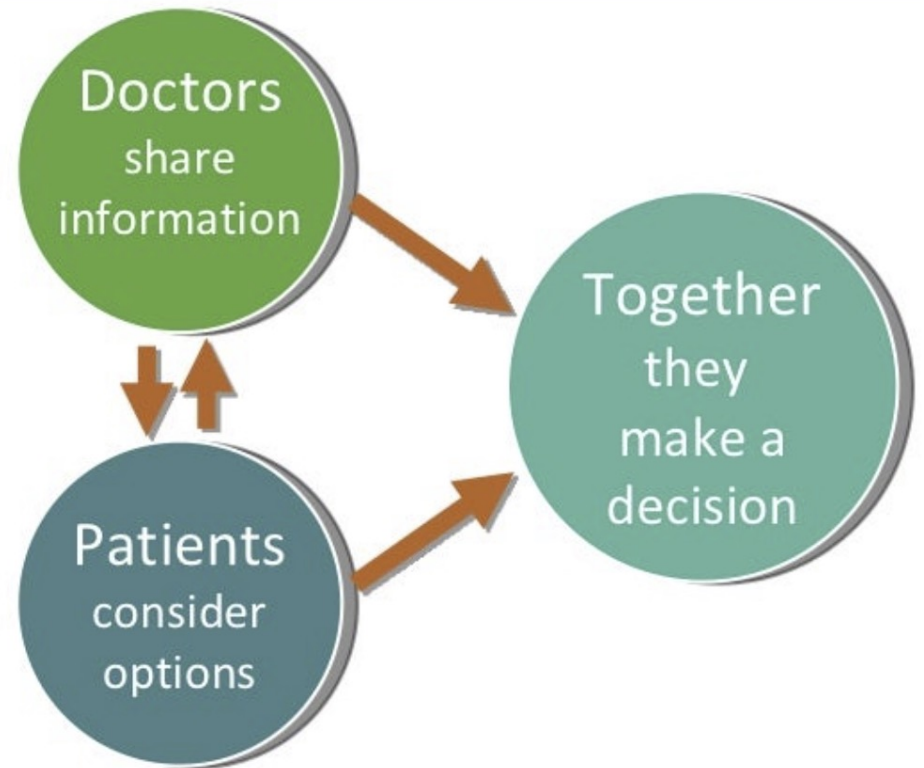
- Bring your family and other loved ones with you to the appointment
- Initiate your **Advance Care Planning**: discuss future medical care with your provider and your loved ones
 - Appoint your Health Care Representative/Surrogate decision maker
 - Complete your Advance Directive and/or update it, as needed



Shared-Decision-Making *Partnership*

A process in which clinicians and patients work together to make decisions regarding “**Whole Person Care**” plans, based on clinical evidence that balances risks and expected outcomes with patient goals, values, and preferences.

- **The patient is the *personal* expert**
- **Medical Providers and/or team are the *clinical* experts**



What Does it mean to have Serious Illness or Terminal Disease?

*1. Likely to
lose most of
my control.*

*2. Need to be
clear about my
top priority.*

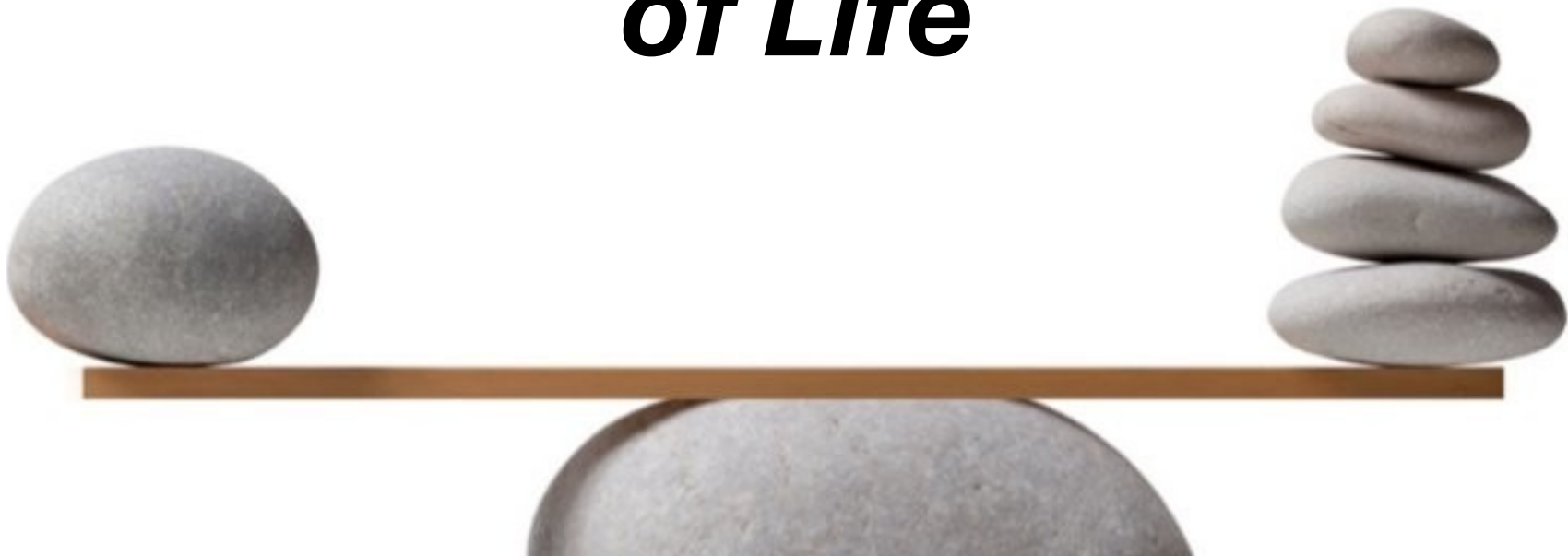
Nobody's life is ever all balanced. It's a conscious decision to choose your priorities every day.

~ Elisabeth Hasselbeck



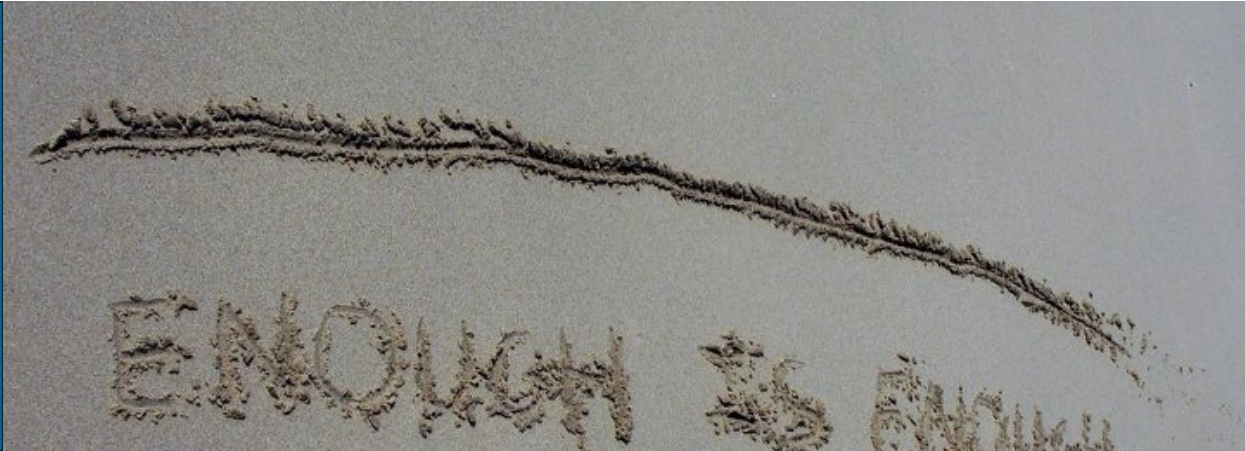
An Ultimate Question

Quality vs. Quantity
of Life



Priorities

What is my line in the sand?



- 1. Which functional and mental compromises are acceptable to me, which could I live with long-term, and which are unacceptable to me?*
- 2. What trade-offs am I willing to make, and for how long, in order to have my desired Quality of Life?*

Prepare Your Loved Ones and Medical Team to Advocate For You!

- “Why do I say that?”
- “Is there anything else that I want them to know?”



Important

Prepare your loved ones to share your priorities with your future medical team.

Can my loved ones provide an empty chair for me and advocate my priorities with my medical team, just as if I were sitting in that chair?

Advance Care Planning/ACP

- Involves discussing and preparing for future decisions about your medical care, should you become very sick and unable to communicate your wishes.
- The most important step is to have meaningful conversations with your loved ones ahead of time.



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My Journey in Advance Care Planning

Time to Get My Ducks in a Row!

Healthy

Less Healthy/Older

Name Surrogate Decision Maker

Complete Advance Directive

Complete POLST

EOL Care Decisions

***Ongoing Conversations and Dialogues
with***

Your Loved Ones and/or Medical Team



Place of Care and Level of Care

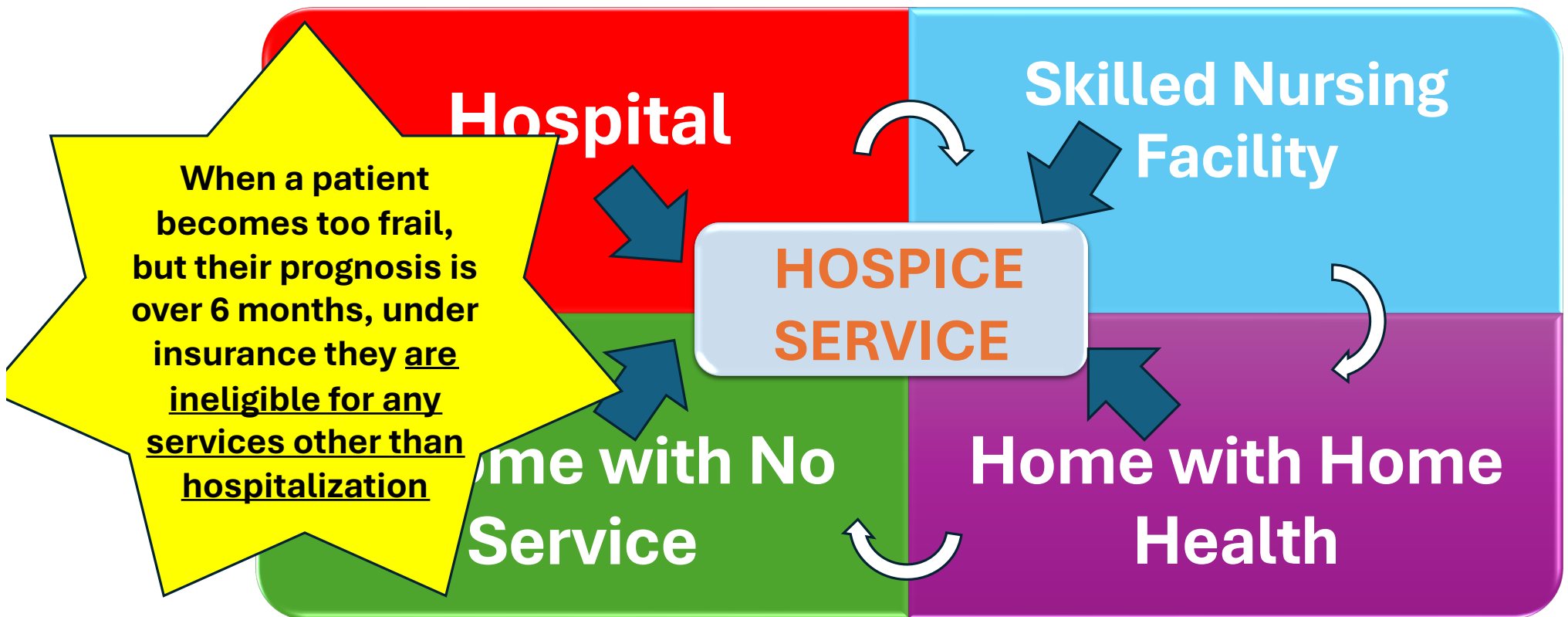
Care Facility Comparison



Facility Type	Level of Care	Services Provided	Typical Residents	Cost	Duration	Regulation
Skilled Nursing Facility	High	24/7 nursing care, rehabilitation, medical supervision	Individuals with serious health issues or recovery needs	High (often covered by insurance)	Short-term to long-term	State and federal regulations, often Medicare certified
Long Term Care Facility	Moderate to High	Personal care, daily living assistance, medical support	Seniors with chronic illnesses or disabilities	Moderate to high	Long-term	State regulations, licensing varies by state
Assisted Living Facility	Moderate	Personal care, medication management, social activities	Seniors who need assistance but are relatively independent	Moderate	Long-term	State licensing and regulations vary; may be less stringent than nursing homes
Adult Foster Care Facility	Moderate	Personal care, meals, companionship in a home-like setting	Seniors or individuals with disabilities needing supervision	Variable (often lower than larger facilities)	Long-term	Varies by state; often requires licensing and regular inspections
Memory Care Facility	High	Specialized care for dementia and Alzheimer's, safety features	Individuals with memory-related issues	High	Long-term	Strict regulations due to specialized care requirements, state licensed

When We Become Very Sick and Unable to Take Care of Ourselves ... Our Journey through Hospital to ...

If a patient's prognosis is 'likely Less than 6 months,' they are eligible for hospice care.



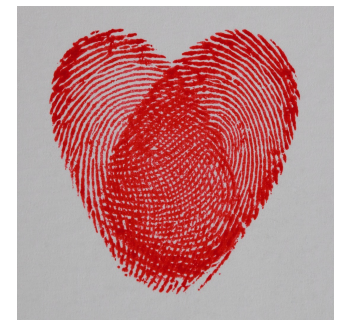
**What Service is Needed
in our Health System?**

Home Palliative Care



Palliative Care focuses on **improving a patient's quality of life** by managing the pain, and other distressing symptoms, accompanying serious illness. Palliative care should be provided along with other medical treatments.

Hospice is palliative care for patients in their **last year of life (<6 months)**. Hospice care can be provided in patient homes, hospice centers, hospitals, long-term care facilities, or wherever a patient resides.



What Service is Needed in our Health System?

The unfortunate truth is that ...

Home Palliative Care

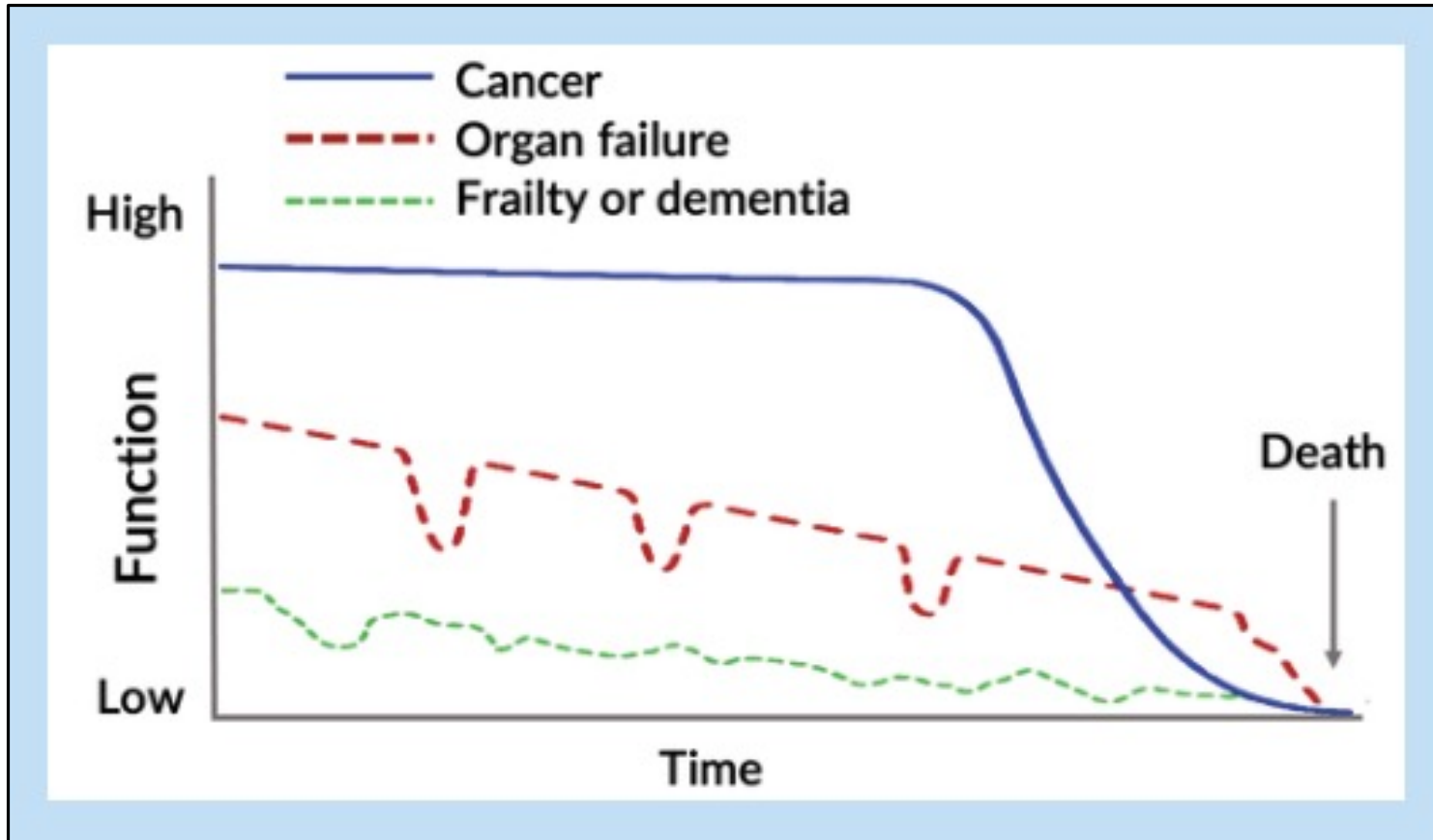


*... is not universally covered
by Medicare/Medicaid and Private Insurers.*



Let's walk through
some serious
illness
trajectories

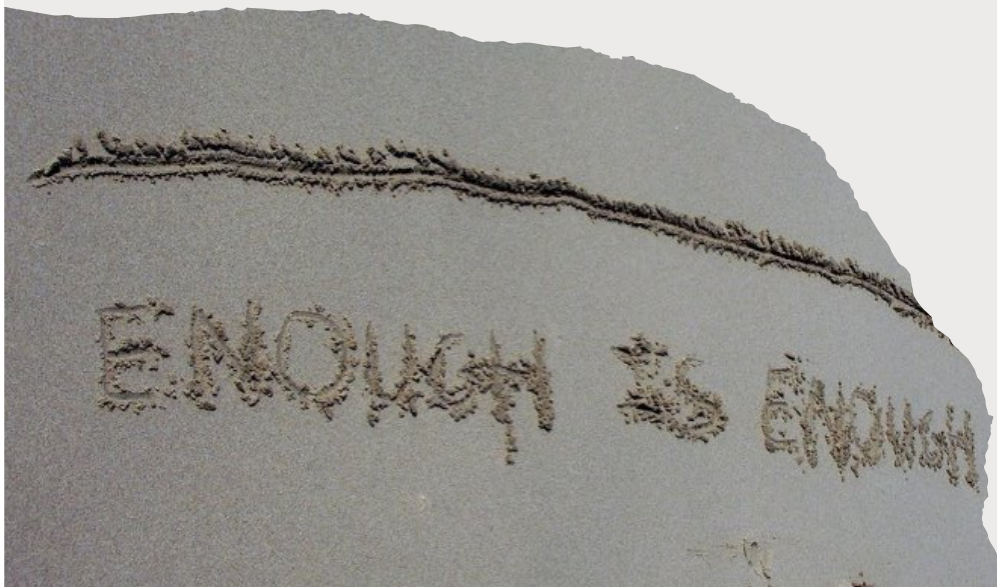
Three Most Common Illness Trajectories



Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age, J. Lynn and D. Adamson

**No matter what the disease,
the process would be...**

**What is My Priority?
~ My Line in the Sand~**



- 1. Which functional and mental compromises are acceptable to me, which could I live with long-term, and which are unacceptable to me?*
- 2. What trade-offs am I willing to make, and for how long, to have my desired Quality of Life?*

Advanced Cancer

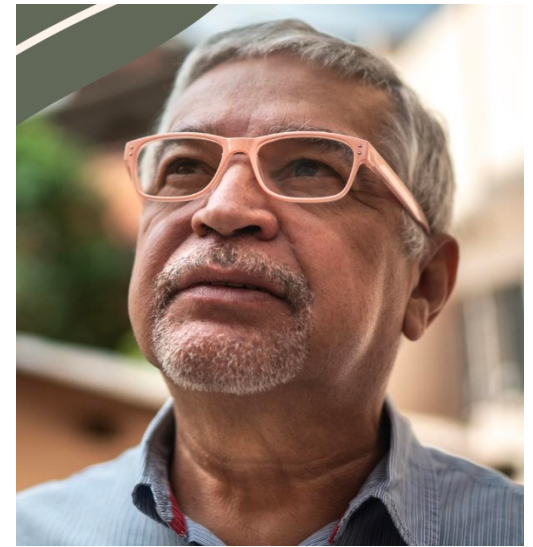
Jose has advanced cancer and is on palliative chemotherapy (not for cure but may extend his life).

He was hospitalized twice, due to severe infections.

He is losing more weight and often in his bed.

- ***Will you try to get back to chemo if it is possible?***
- ***When would you stop?***

Jose, Age 68

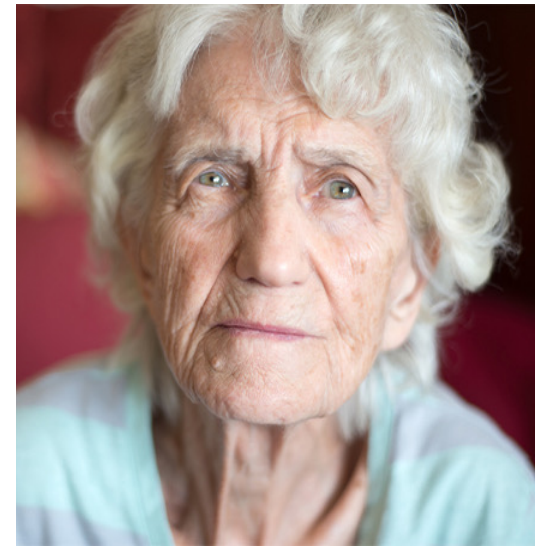


Advanced Heart Disease

Joanne has been in and out of hospital over the past 6 months due to heart failure. Most recently, she was admitted to an Intensive Care Unit and required intubation. She was discharged to a Skilled Nursing Facility yet does not appear to be improving back to her baseline and has been confused off and on.

- ***Would you go back to the hospital if you got worse again?***
- ***Would you be willing to go through intubation again?***

Joanne, Age 88



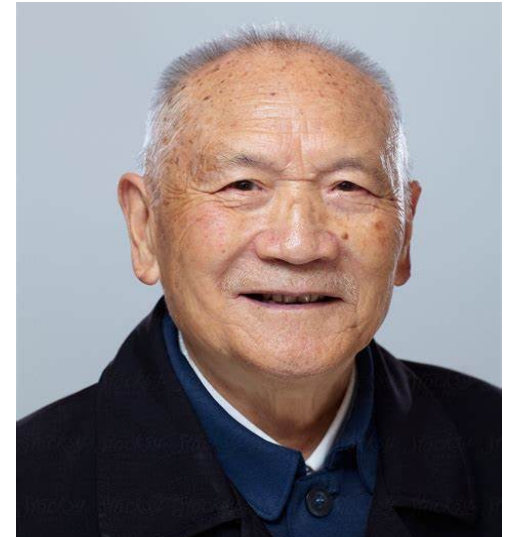
End Stage Renal Disease on Dialysis

Wei has been on dialysis for 10 years but recently has not tolerated it well.

He has been in and out of hospital several times due to dialysis complications.

- *Would you continue the status quo or stop dialysis?*
- *Note: if you stop dialysis, likely will die in 7-9 days.*

Wei , Age 82



Frequent Falls and Fractures

June lives alone, where she has had 5 falls, the most recent of which resulted in a fractured hip, requiring surgery.

It is very unsafe for her to live alone any longer.

- *Would you be willing to move away from your home?*

June, Age 76



Advanced Dementia

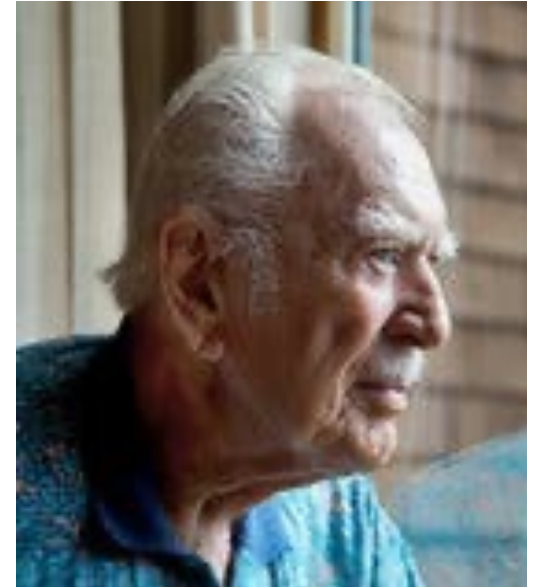
George has Alzheimer's dementia for over 8 years.

He does not recognize his family most of the time. He has been in memory care for the past 2 years.

He is losing weight, has difficulty swallowing, has had aspiration pneumonia several times, and has been admitted to the hospital.

- *How would you prepare for this situation?*

George, Age 78



Permanently Unconscious

Martha was in an auto accident and has been unconscious ever since.

Her doctors have determined that she is in a ***persistent vegetative state*** and it is highly unlikely that she will ever meaningfully interact with others or be able to care for herself.

- ***How would you prepare for this situation?***

Martha, Age 58



In Reality, Patients Can Have Many More Complicated Situations at Once

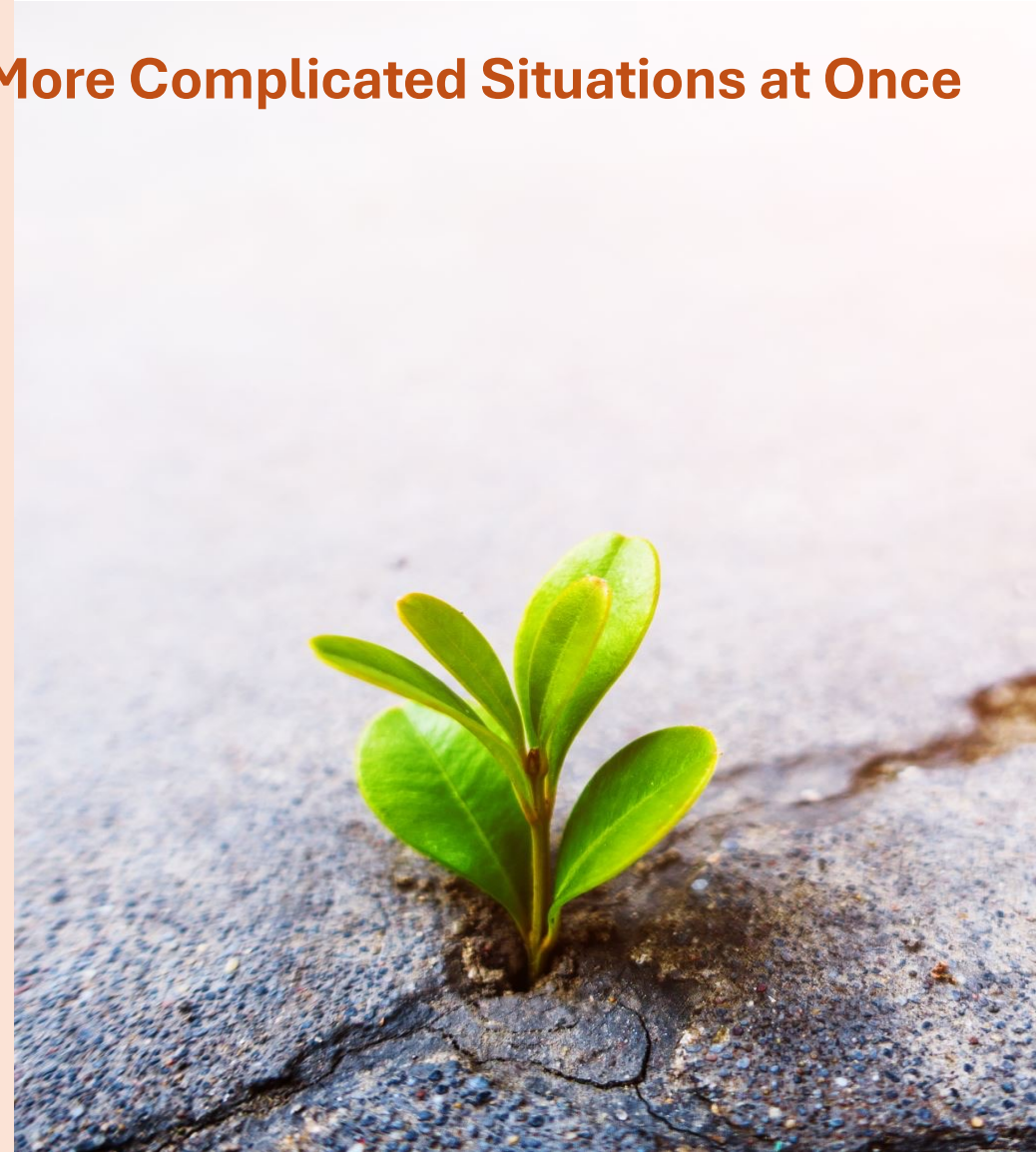
It is most important now that you:

No matter what the disease process would be ...

1. Which functional/mental compromises are acceptable to me, which could I live with long term, and which are unacceptable?
2. What trade-offs am I willing to make, and for how long, to have my desired quality of life? (“The Banana Talk!”)

AND

1. Always be kind to and love your family and friends
2. Establish and cultivate a primary care provider that you can trust
3. Establish and cultivate a medical team that you can trust
4. Prepare your priorities and tell them to the people who will advocate for you



The Quintuple Aims of Medicine

Who Benefits
from
Preparing for
the Future?

Best
Possible
Health
Outcome

All of US!
It is OUR
Obligation!!

Equity &
Accessibility

Best Use of
Resources

Improved
Patient
Experience

Workforce
Well-Bing





KEY TAKEAWAYS

- 1. Serious illness is not necessarily a terminal condition.**
- 2. Initiate Advance Care Planning → Establish your priorities and prepare your loved ones who will advocate for you.**
- 3. Establish and cultivate a primary care provider/medical team you can trust.**
- 4. Talk to Politicians to improve OUR serious illness care model.**
- 5. Always be kind to and love your family and friends!**