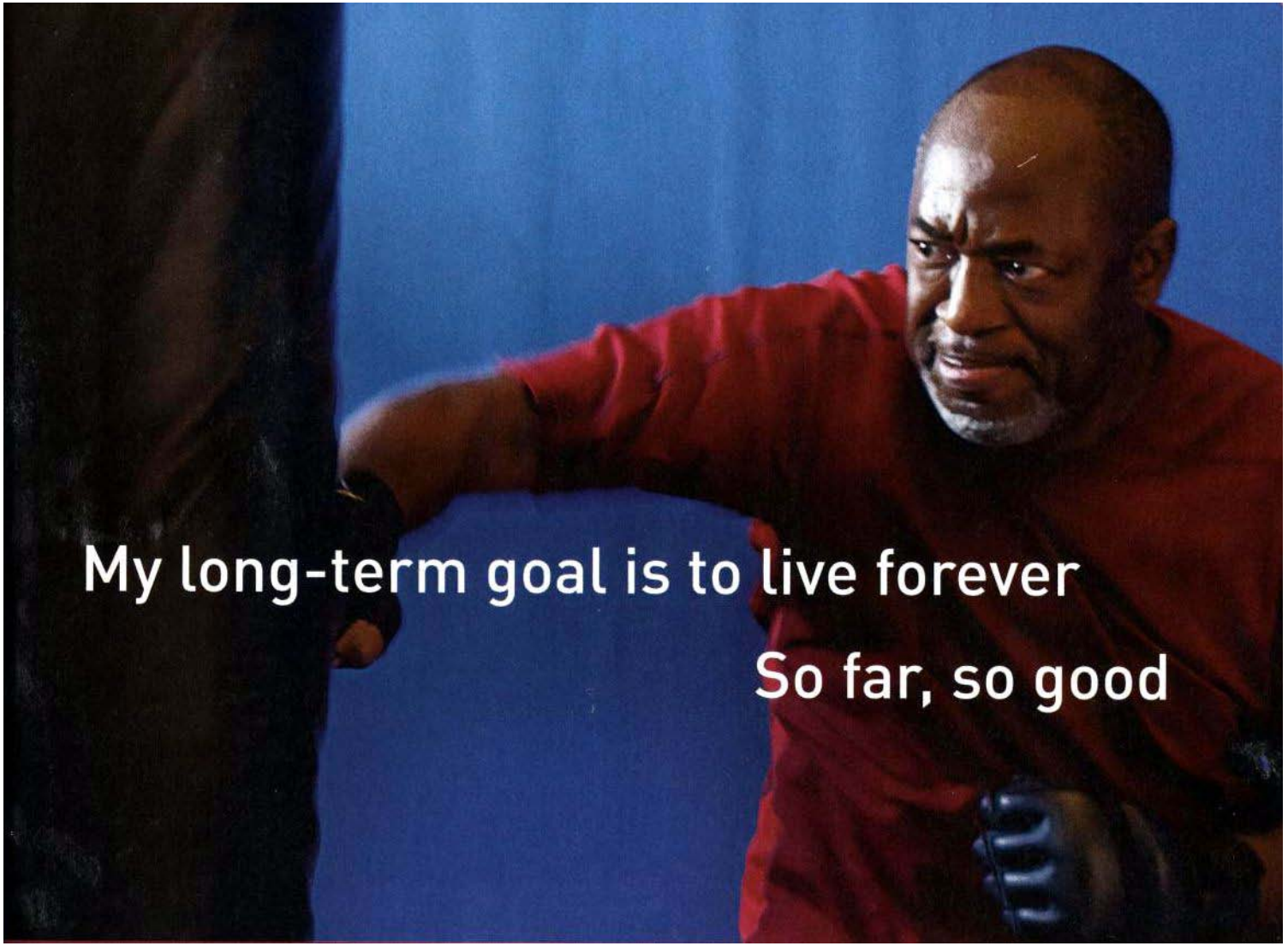
End of life care: definitions and decisions

Leslie J Blackhall MD MTS
Palliative Care Service
UVA School of Medicine

Why study end of life care?

- End of life care is part of the continuum of care for all patients.
- Dying is a part of every life.

"What should medicine do when it can't save your life?" Atul Gawande


My long-term goal is to live forever
So far, so good

If your plan is to live forever…

You’re gonna have a bad time

Goals of Medicine

What is the purpose of each of these treatments, and what are the drawbacks (if any) to performing them?

- Surgery to remove the spleen of a previously healthy patient who has had a car accident and suffered multiple life threatening injuries, including a splenic laceration.

- Placement of a feeding tube in a patient who is unable to swallow has had a head injury and is comatose. His physicians believe that he will never be fully conscious again.

- Mechanical ventilation for a patient with incurable cancer and pneumonia causing respiratory failure.

Why study end of life care?

- Dying is a part of the life cycle, and patients facing this part of life need medical care appropriate to their condition.
- Physicians (and patients) usually see the job of the doctor as saving life, and thus can have trouble when faced with the prospect of caring for patients who have incurable illness.

Why study end of life care?

- Because everyone eventually dies, we must consider what constitutes good medical care for patients who are approaching the end of life.
- 25% or more of Medicare dollars are used for care in the last year of life.
- Much of this is spent on chronic, progressive, incurable illnesses.

Palliative care

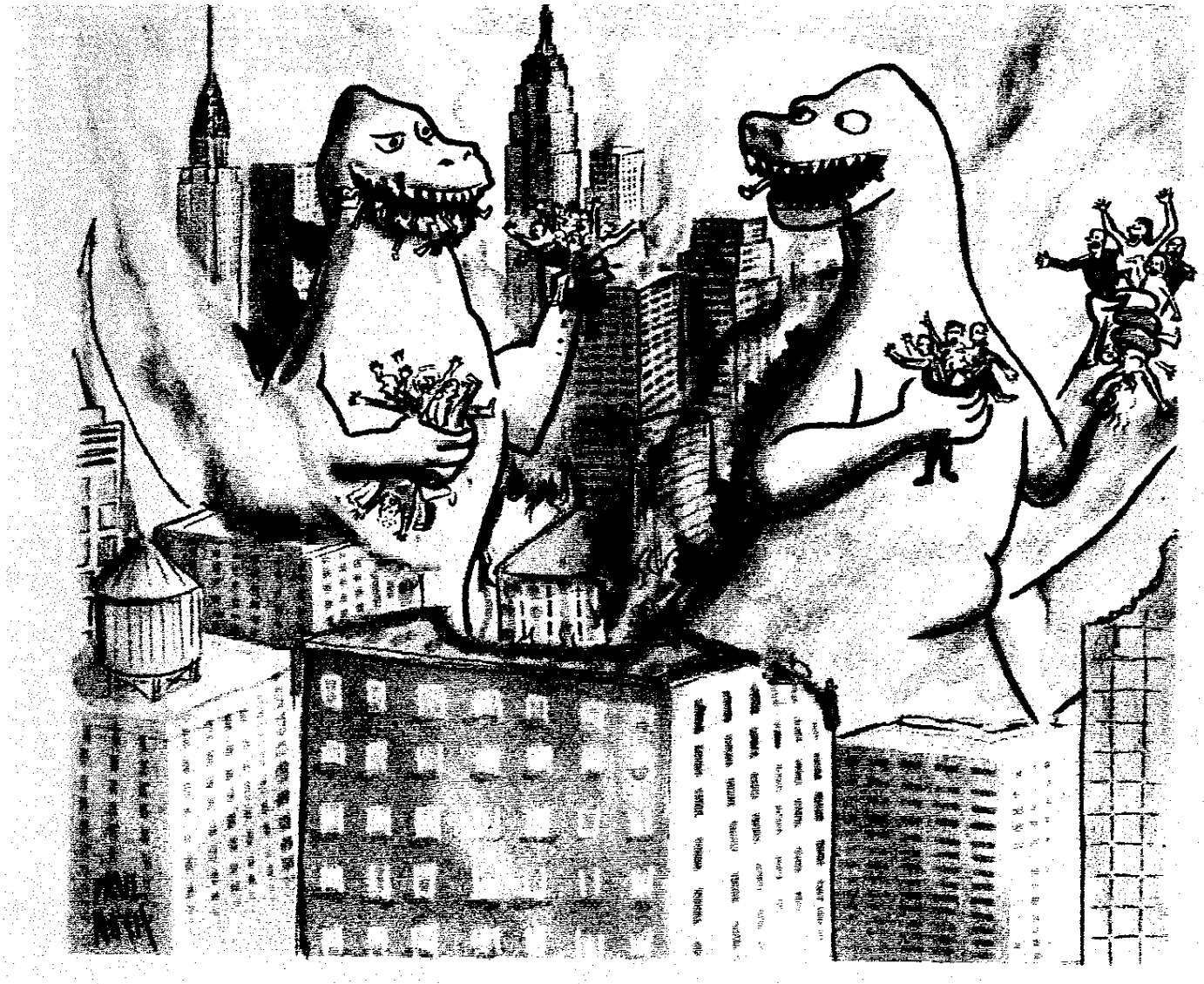
- Specialized area of healthcare that specializes in improving quality of life and relieving symptoms patients with serious illness. Usually focused on patients with chronic, progressive illnesses and those nearing the end of life.

Palliative care

- In addition to expert symptom management, palliative care focuses on helping patients and families make decisions about *goals of care.*
- Multidisciplinary approach address physical, emotional, spiritual, and social concerns that arise with advanced illness.

Hospice care

- An insurance benefit under Medicare, Medicaid and most private insurance programs.
- Patients must have 6 month or less to live, on average.
- Focus is on helping patients and families with troubling symptoms, by bringing a multidisciplinary approach to the patient at home.



"Of course you feel great. These things are loaded with antidepressants."

Most common causes of death in adults (over the age of 35)

- Cancer
- Heart disease, especially CHF
- Pulmonary disease, especially COPD
- Cerebrovascular disease
- Alzheimer's dementia (elderly)

What do we mean when we say someone is dying?

- Patient is a 75 yo white woman with bladder cancer metastatic to lung.
- She is tolerating chemotherapy well, and is currently on vacation with her daughters in NYC. She is able to walk around the city, enjoying the food and museums.

- Is she dying?

What do we mean when we say someone is dying?

- 8 months later, she needs more help at home. Her children do her grocery shopping and clean the house. She has lost weight and is tired easily. She has trouble remembering to take her pills.
- She enjoys having lunch out with her friends, and seeing her grandchildren.
- Is she dying?

What do we mean when we say someone is dying?

- 2 months after that, she is lying on a hospital bed at home. She is unresponsive, and has been so for 48 hours. She has a rapid heart beat, and cool extremities.
- Is she dying?

What do we mean when we say someone is dying?

Nobody lives forever.

Does that mean we're all dying?

What do we mean when we say someone is dying?

That word doesn't really seem helpful, as a guide to how we practice medicine, does it?

End of life care: some definitions

- **Life threatening illness**
- **Permanent alteration of functional status**
- **Life-limiting illness**

Life-threatening illness

- **Potentially, but not necessarily fatal illness.**
- For example: serious car accident resulting in major trauma, severe infection, early stage breast cancer.
- Patients with life-threatening illnesses may come to the brink of death and be saved by medical care, and return to a normal quality of life.

Permanent alteration of functional status

- **An illness or injury that has led to a permanent, severe change in functional status**. For example: anoxic encephalopathy, massive intracranial hemorrhage, or other conditions leading to persistent vegetative state or the minimally conscious state.
- Life could be maintained but quality of life of patient is such that it is not clear that they would want to have it prolonged.

Life-limiting illness

- **An incurable, progressive illness which will eventually result in the patient's death**, although it may take many years.
- Advanced cancer (most widely metastatic solid tumors), end-stage congestive heart failure or pulmonary disease, Alzheimer's dementia.
- Most of the leading causes of death in adults are these life-limiting illnesses.

Life-limiting illness

- Medical care can prolong life and improve quality of life but cannot cure these illnesses
- Patients with life-limiting illnesses will eventually die of this illness. As their disease progresses they have an illness trajectory from having a life-limiting illness, to being terminally ill with that illness, to actively dying.

Terminal illness

- As life limiting illnesses progress, patients become terminally ill.
- Deteriorating functional status and failure to respond to treatments of underlying condition are hallmarks of this phase of a life-limiting illness.
- Limited options, if any, to prolong life, death likely within months.

Actively dying

- People with life limiting illnesses who are at the very end of life are in the process of actively dying.
- Minimally responsive or unresponsive.
- No longer eating or drinking.
- Bedbound.
- Altered breathing patterns.
- Usually have hours to days to live

What do we mean when we say someone is dying?

- Patient is a 75 yo white woman with bladder cancer metastatic to lung.
- She is tolerating chemotherapy well, and is currently on vacation with her daughters in NYC. She is able to walk around the city, enjoying the food and museums.

- *She has a life-limiting illness.*

What do we mean when we saysomeone is dying?

- 8 months later, she needs more help at home. Her children do her grocery shopping and clean the house. She has lost weight and is tired easily. She has trouble remembering to take her pills.
- She enjoys having lunch out with her friends, and seeing her grandchildren.
- *She is terminally ill.*

What do we mean when we say someone is dying?

- 2 months after that, she is lying on a hospital bed at home. She is unresponsive, and has been so for 48 hours. She has a rapid heart beat, and cool extremities.

  She is actively dying.

Use of life-supporting technology: **life threatening illness**

- CPR, mechanical ventilation and artificial feeding are techniques originally developed for patients with acute, life threatening illnesses.
- In this setting, they are used to support the patient's life, while the patient is undergoing treatment aimed at reversing the underlying cause of cardiac or pulmonary failure.

Use of life-supporting technology: **permanent alteration of functional status**

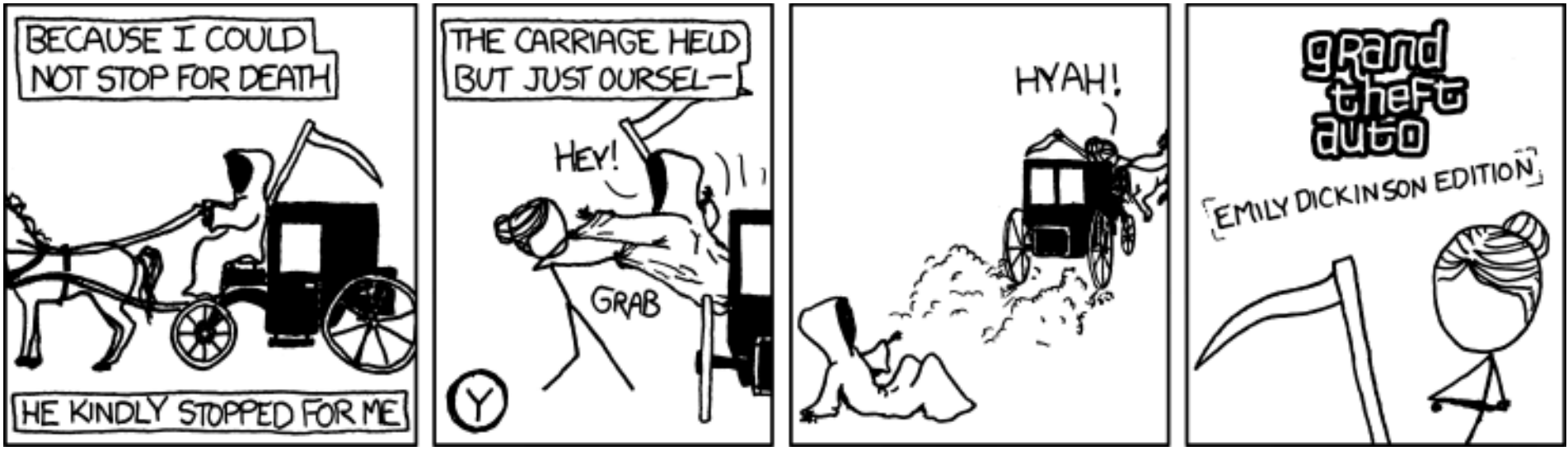
- Most of the famous bioethics cases involve this situation.
- Patient could live a long time in a vegetative state if artificial feeding and treatment of complications life infections are continued.
- Patients and their families have a right to chose if they would want this type of life prolongation.

Use of life-prolonging technology: **life-limiting illness**

- All patients with life-limiting illnesses while eventually develop cardiac and respiratory failure at the end of life as part of the normal illness trajectory.
- Life supporting technology is less effective (often much less effective) in these conditions, because the underlying condition causing cardiopulmonary failure cannot be reversed.

Life-limiting illness

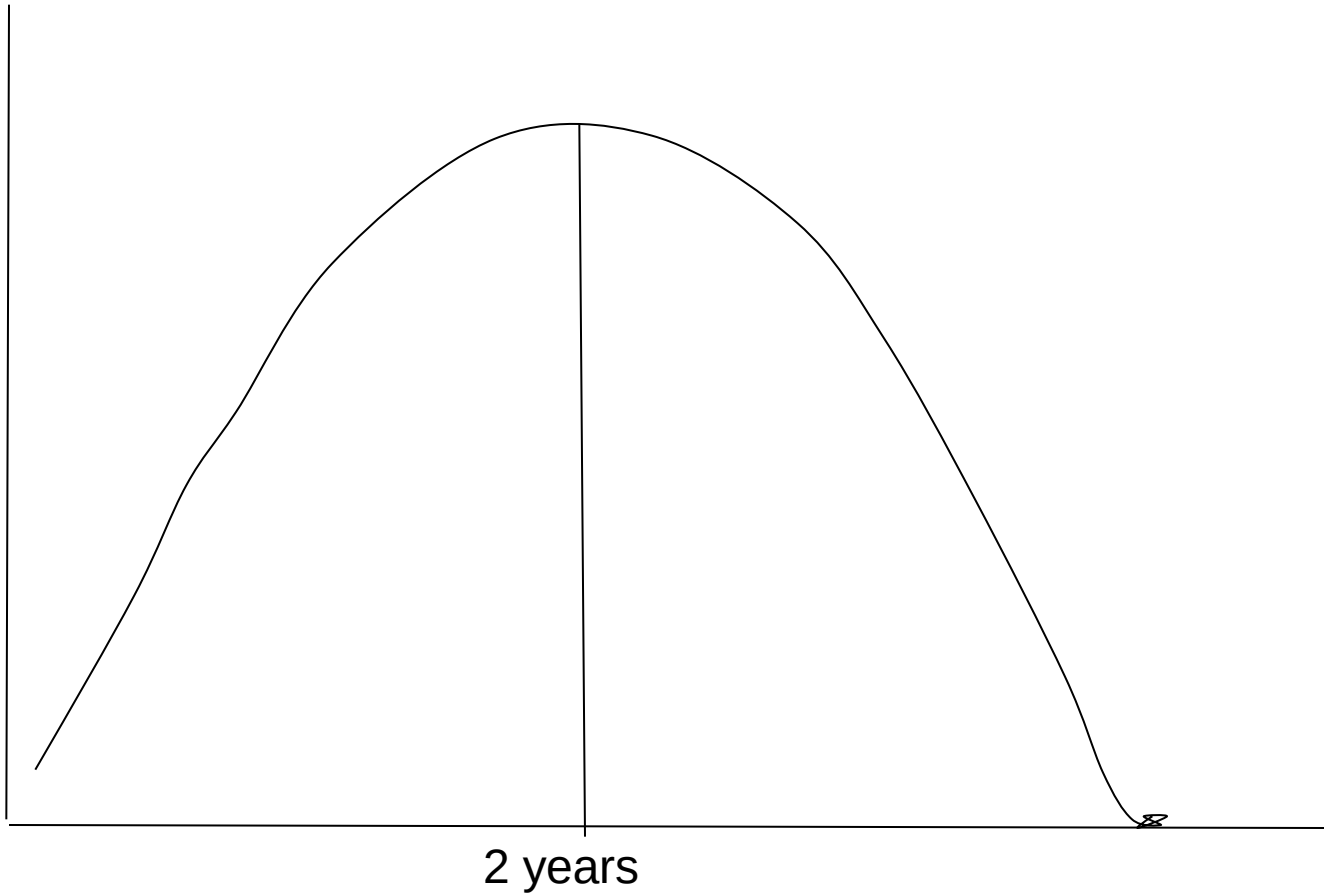
- The number of patients with these illnesses are increasing as our population ages
- A large percentage of spending on health care is devoted to these conditions.
- Physicians, patients and family members struggle with how best to care for these illnesses.


BECAUSE I COULD NOT STOP FOR DEATH
HE KINDLY STOPPED FOR ME
THE CARRIAGE HELD BUT JUST OURSEL—
HEY!
GRAB
Y
HYAH!
grand theft auto
EMILY DICKINSON EDITION

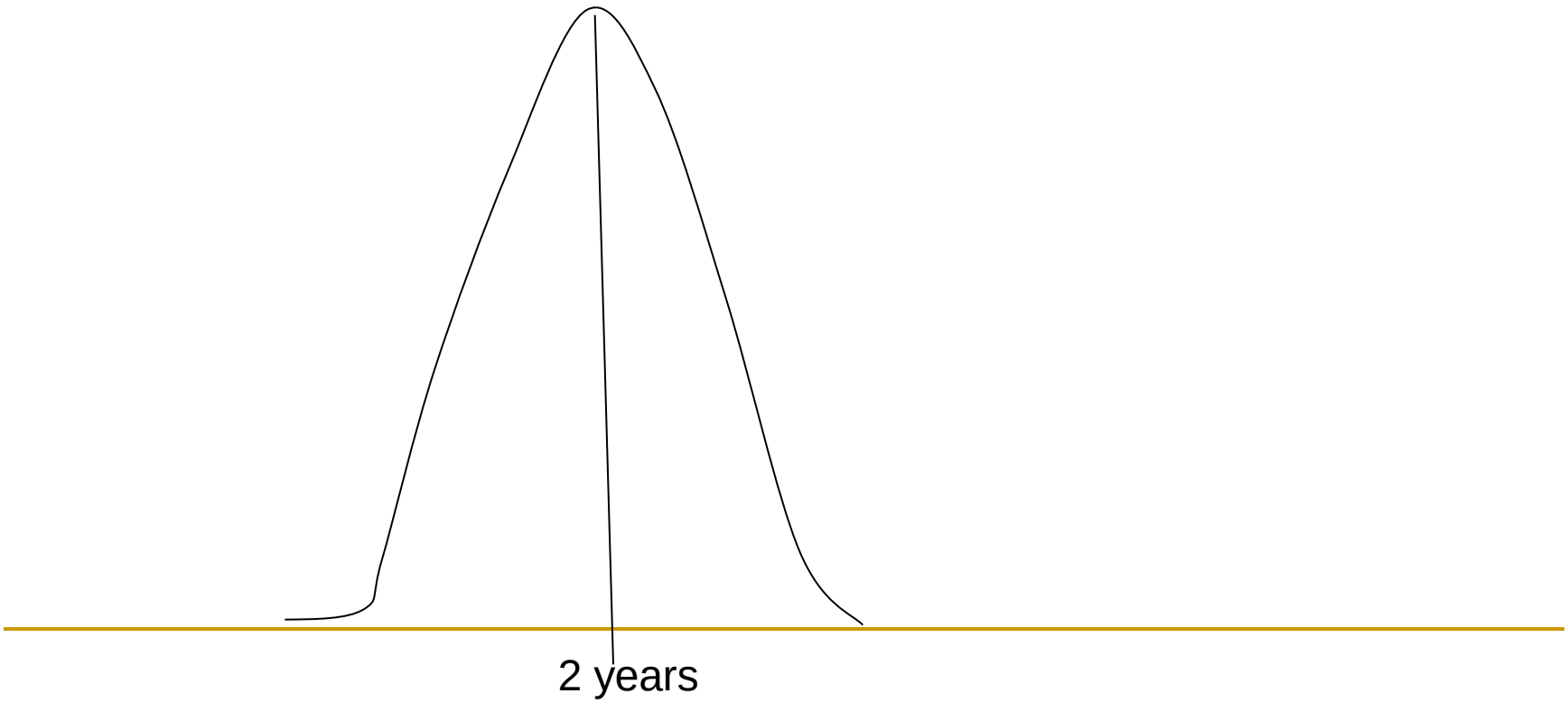
Life-limiting illnesses: how do we care for our patients?

- Illness trajectory
- Prognosis

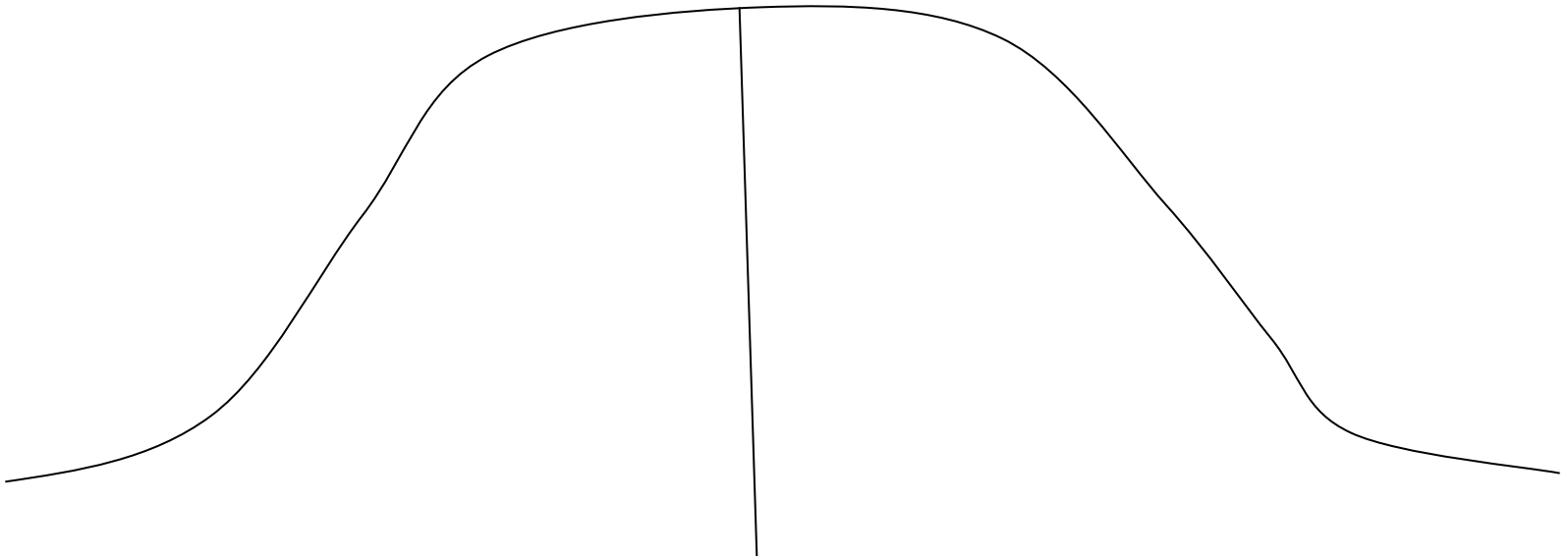
Prognosis of an individual is different than prognosis of a group of individuals



Prognosis of an individual is different than prognosis of a group of individuals



Prognosis of an individual is different than prognosis of a group of individuals



Prognosis of an individual is different than prognosis of a group of individuals

- It is easier to describe the prognosis of a group of people with a given illness, than to predict the prognosis of an individual in that group.
- It is more accurate to talk about the average survival of a group, and include the range.
- We can also try to use additional factors to help us understand the likely survival of individual patients.

Prognosis and functional status

- One of the measures that has been shown to best predict prognosis for a variety of patients with life-limiting illnesses is functional status.
- Functional status is the ability of an individual to function physically and mentally, and to stay well nourished.
- The Palliative Performance Scale is an example of a tool which uses functional status to predict prognosis.

PALLIATIVE PERFORMANCE SCALE (PPS)

Anderson, Fern et al. (1996) Palliative Performance Scale (PPS) a new tool. Journal of Palliative Care 12(1), 5-11

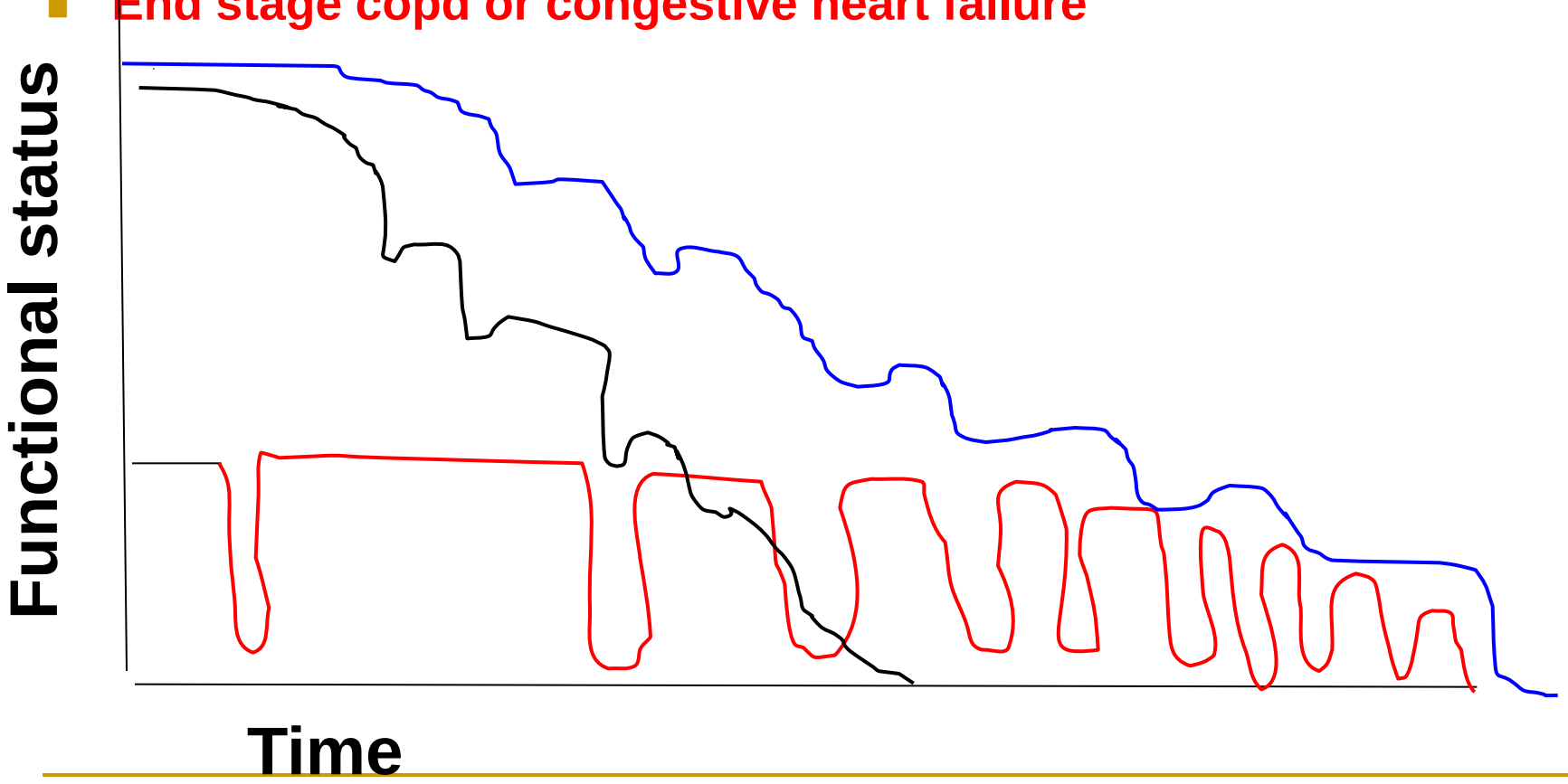
%	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
100	Full	Normal Activity No Evidence of Disease	Full	Normal	Full
90	Full	Normal Activity Some Evidence of Disease	Full	Normal	Full
80	Full	Normal Activity with Effort Some Evidence of Disease	Full	Normal or Reduced	Full
70	Reduced	Unable Normal Job / Work Some Evidence of Disease	Full	Normal or Reduced	Full
60	Reduced	Unable Hobby / House Work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
50	Mainly Sit/Lie	Unable to Do Any Work Extensive Disease	Considerable Assistance Necessary	Normal or Reduced	Full or Confusion
40	Mainly in Bed	As Above	Mainly Assistance	Norma or Reduced	Full or Drowsy or Confusion
30	Totally Bed Bound	As Above	Total Care	Reduced	Full or Drowsy or Confusion
20	As Above	As Above	Total Care	Minimal Sips	Full or Drowsy or Confusion
10	As Above	As Above	Total Care	Mouth Care Only	Drowsy or Coma
0	Death	-	-	-	-

Illness trajectory

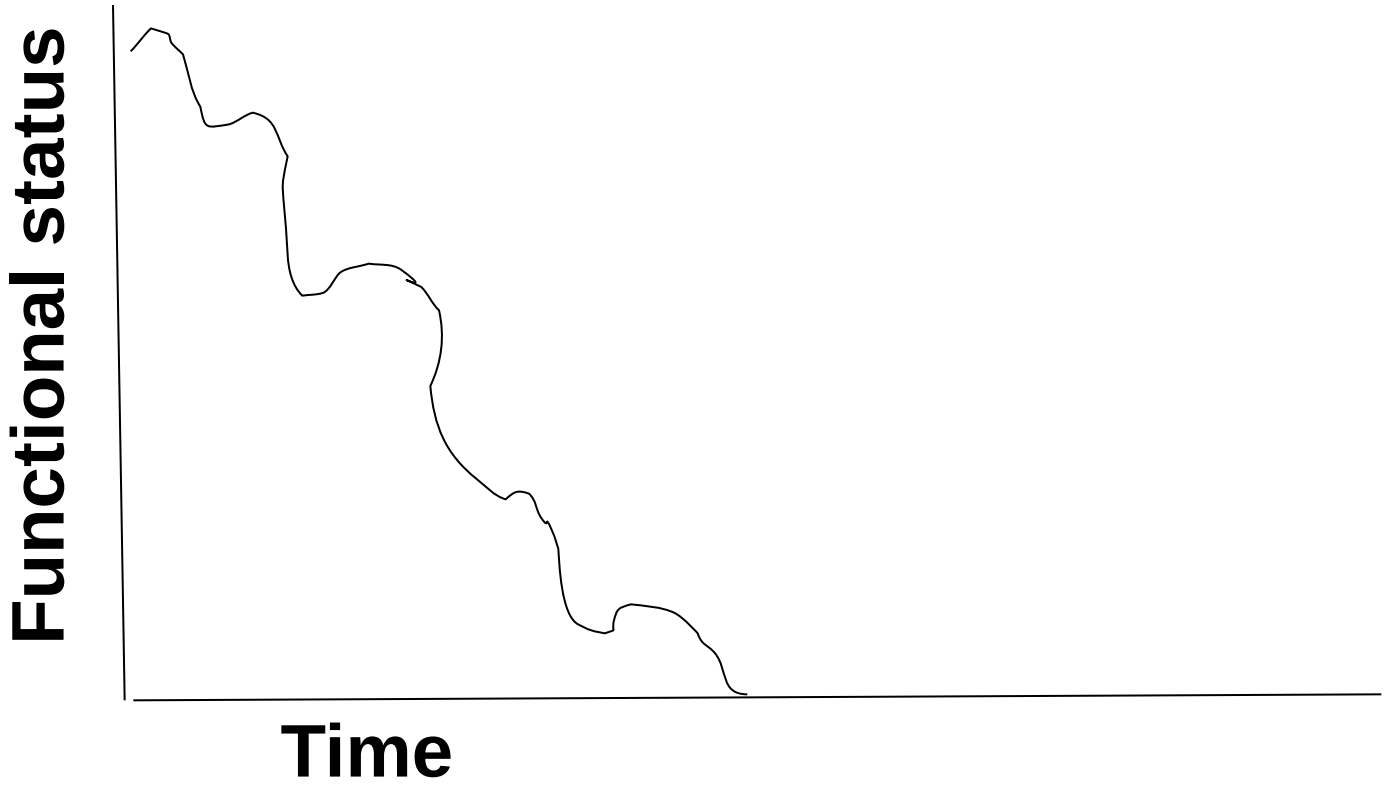
- Natural history of a chronic progressive (life-limiting) disease.

Illness trajectories for life-limiting illnesses

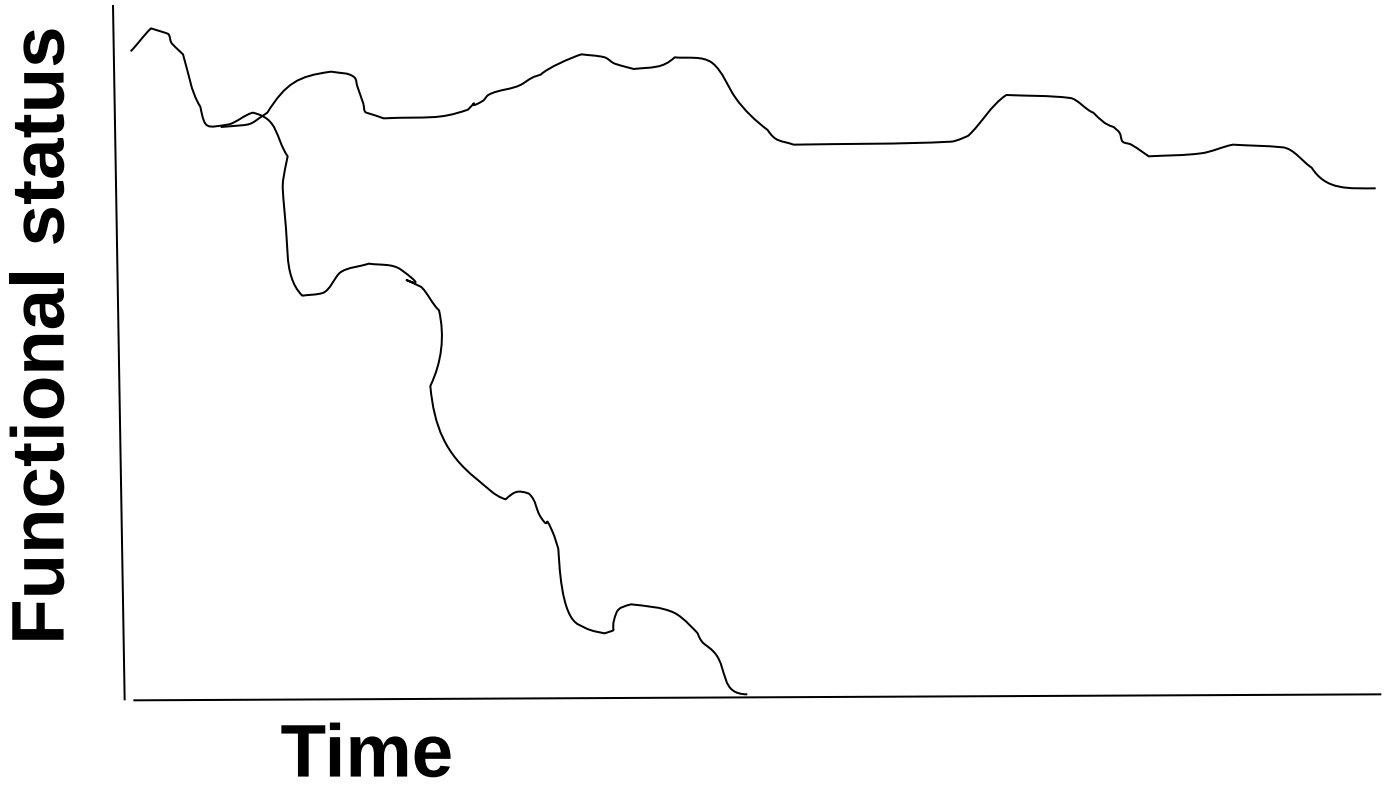
- **Dementia**
- **Metastatic lung cancer (stage 4)**
- **End stage copd or congestive heart failure**



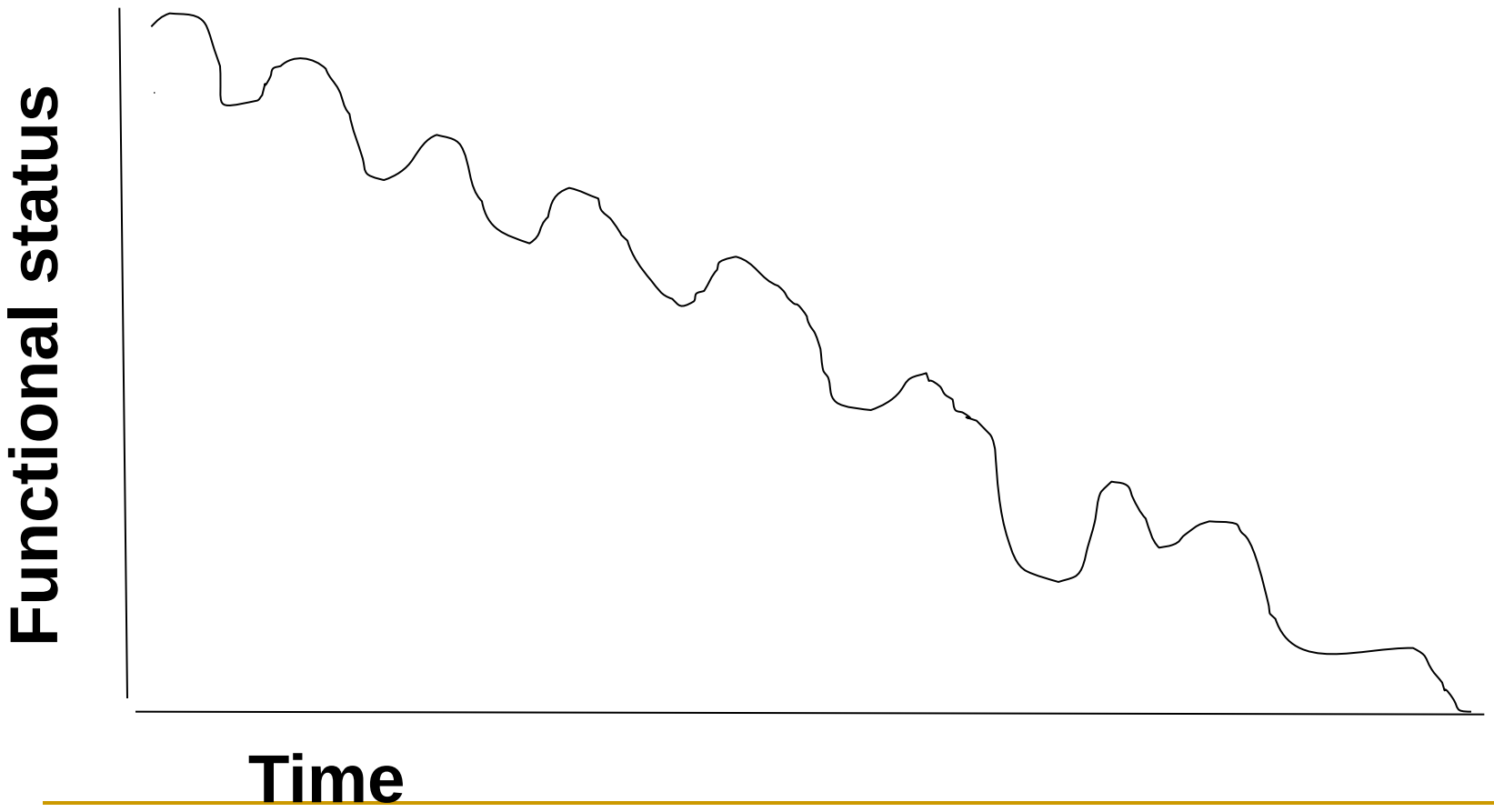
HIV disease, 1984 (before HAART)



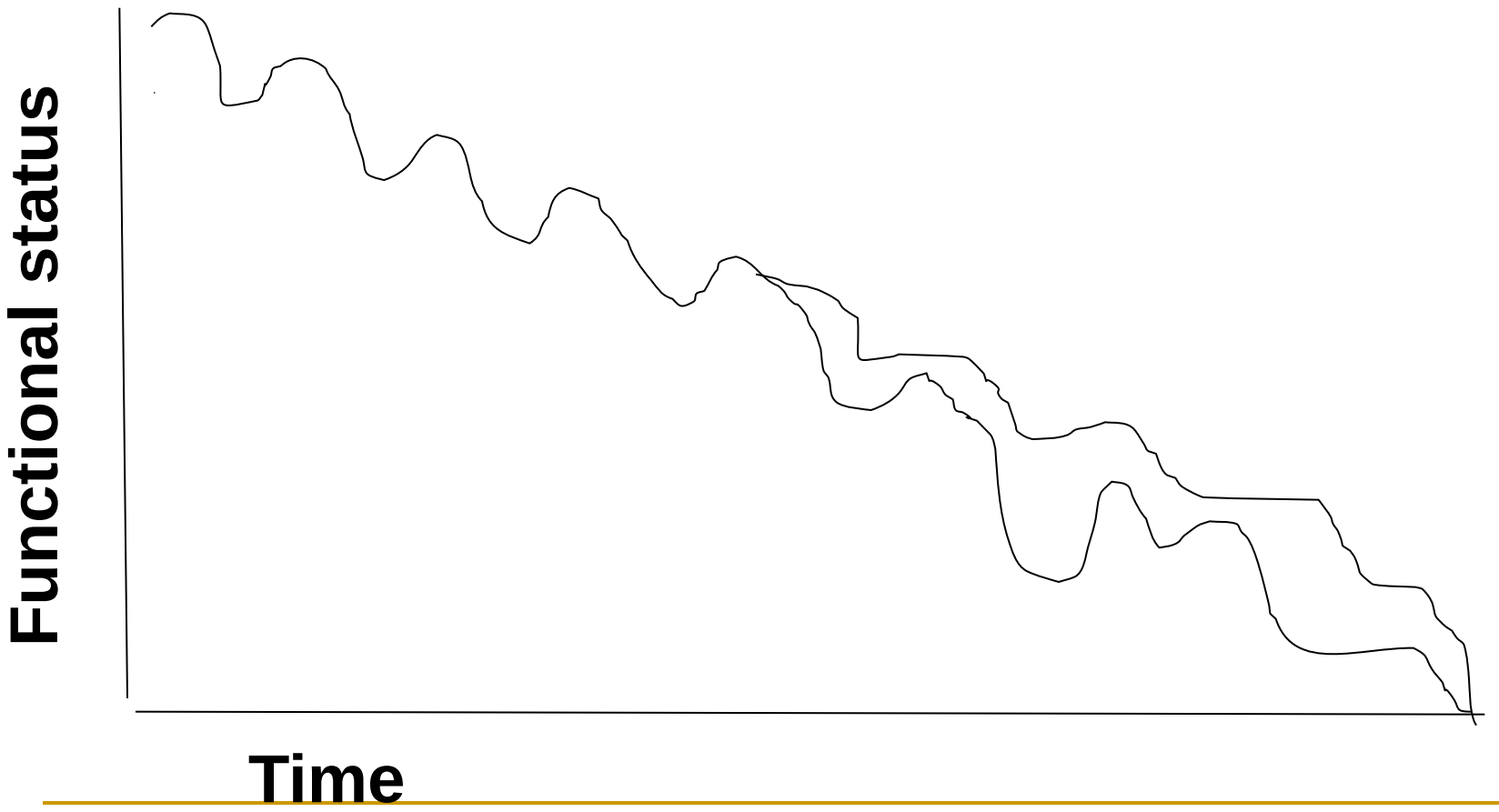
HIV disease, (after HAART)



Alzheimer's type dementia



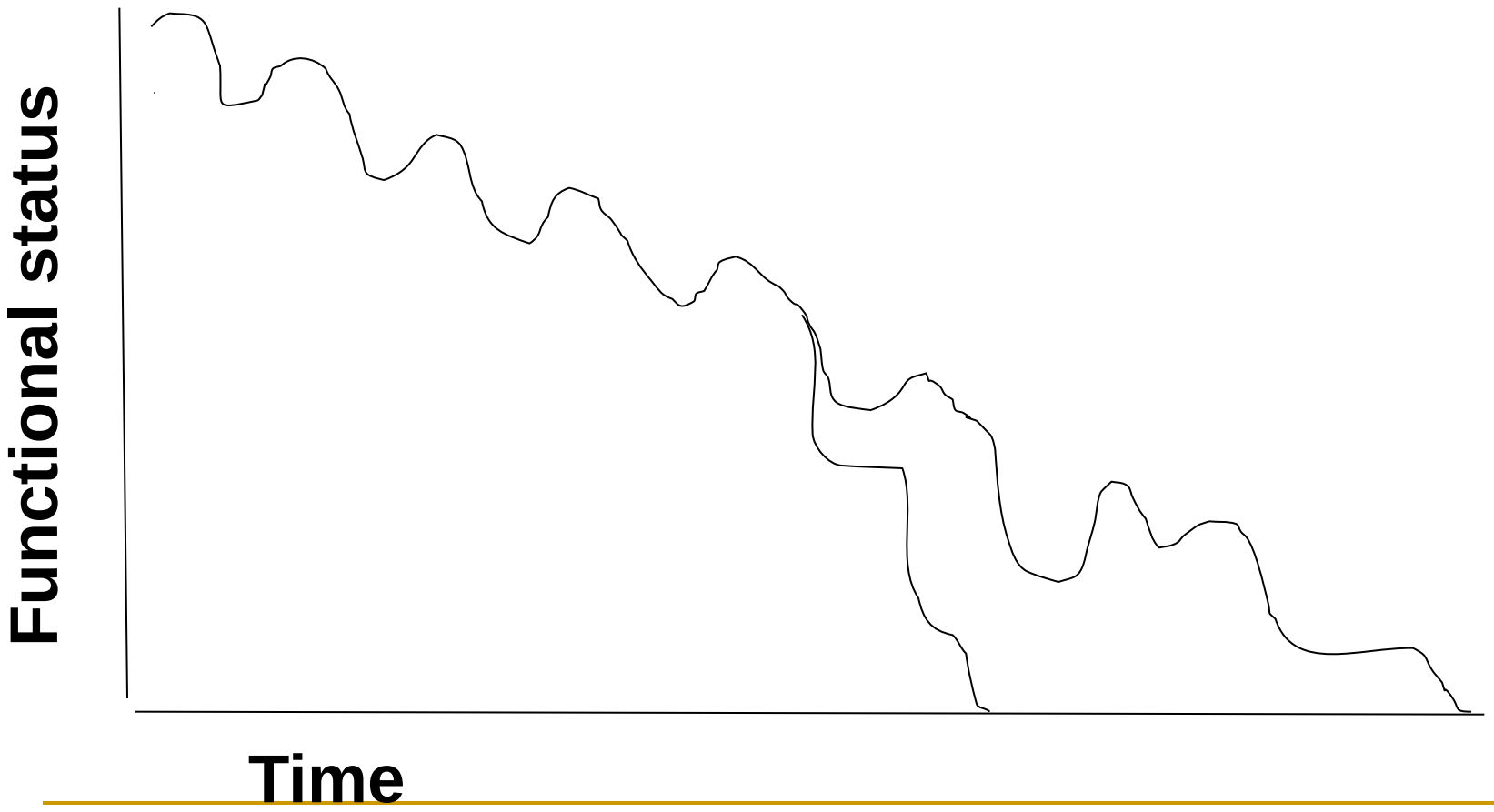
Dementia, with Aricept



Alzheimer's dementia illness trajectory

- As functional status declines, patients with Alzheimer's dementia develop complications which include difficulties swallowing and decreased appetite
- Aspiration pneumonia is a common way patients with this illness die.

End of life decisions in dementia: should you treat this pneumonia?



End of life decisions in dementia: should you treat this pneumonia?

Goals of care

- Treating aspiration pneumonia in patients with Alzheimer's dementia will not cure the dementia or even prevent further decline in the future.
- Such aspiration events will likely recur in the future.
- If treatment of the pneumonia is successful it may prolong life and reverse acute symptoms.

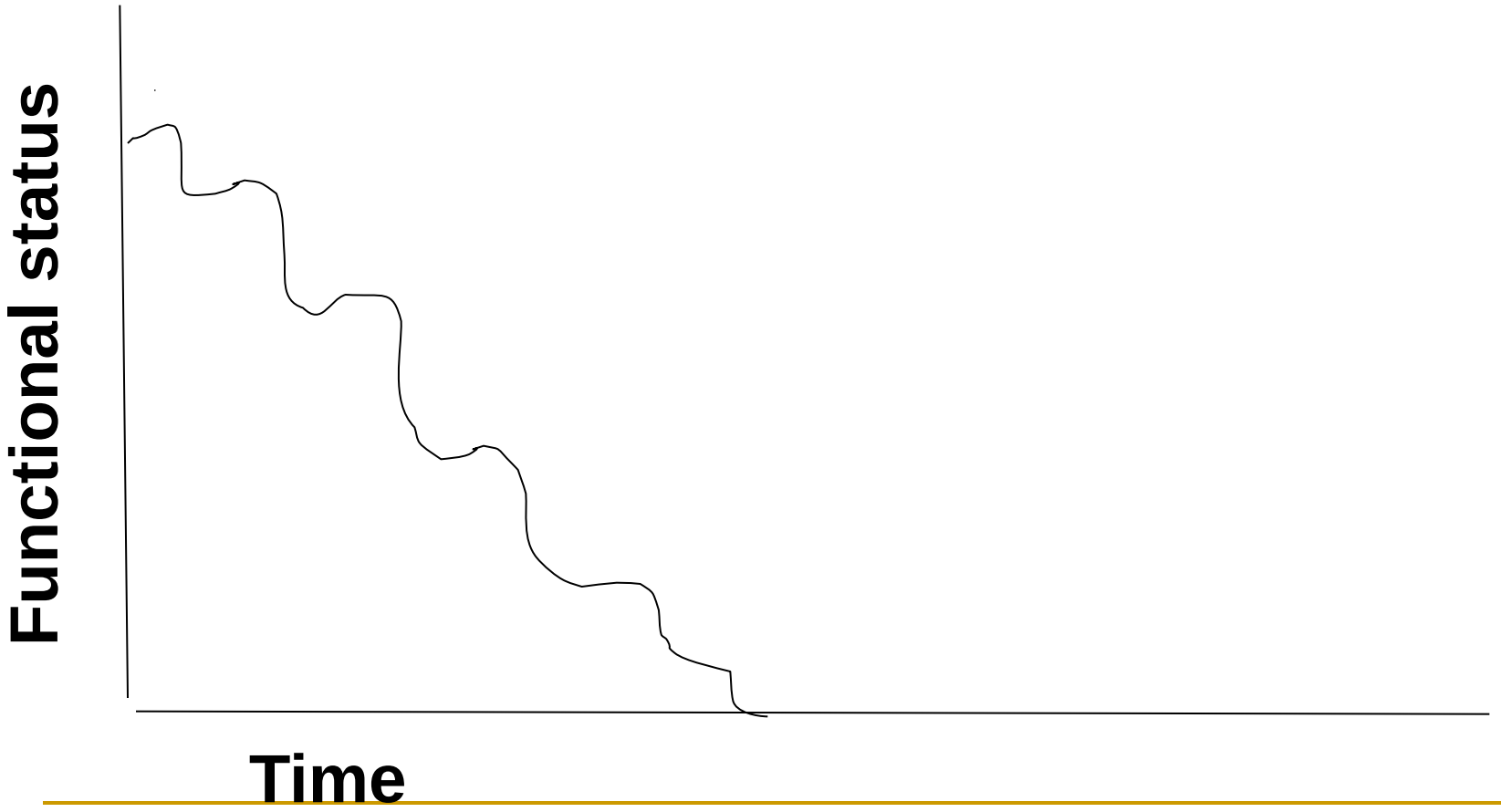
Goals of care

- If patient develops respiratory failure, should we use mechanical ventilation or CPR?
- There are ethical aspects to these questions, but medically speaking we also need to know: how well do those interventions work?
- Do these interventions prolong life or improve the quality of life for people with advanced dementia?

Goals of care

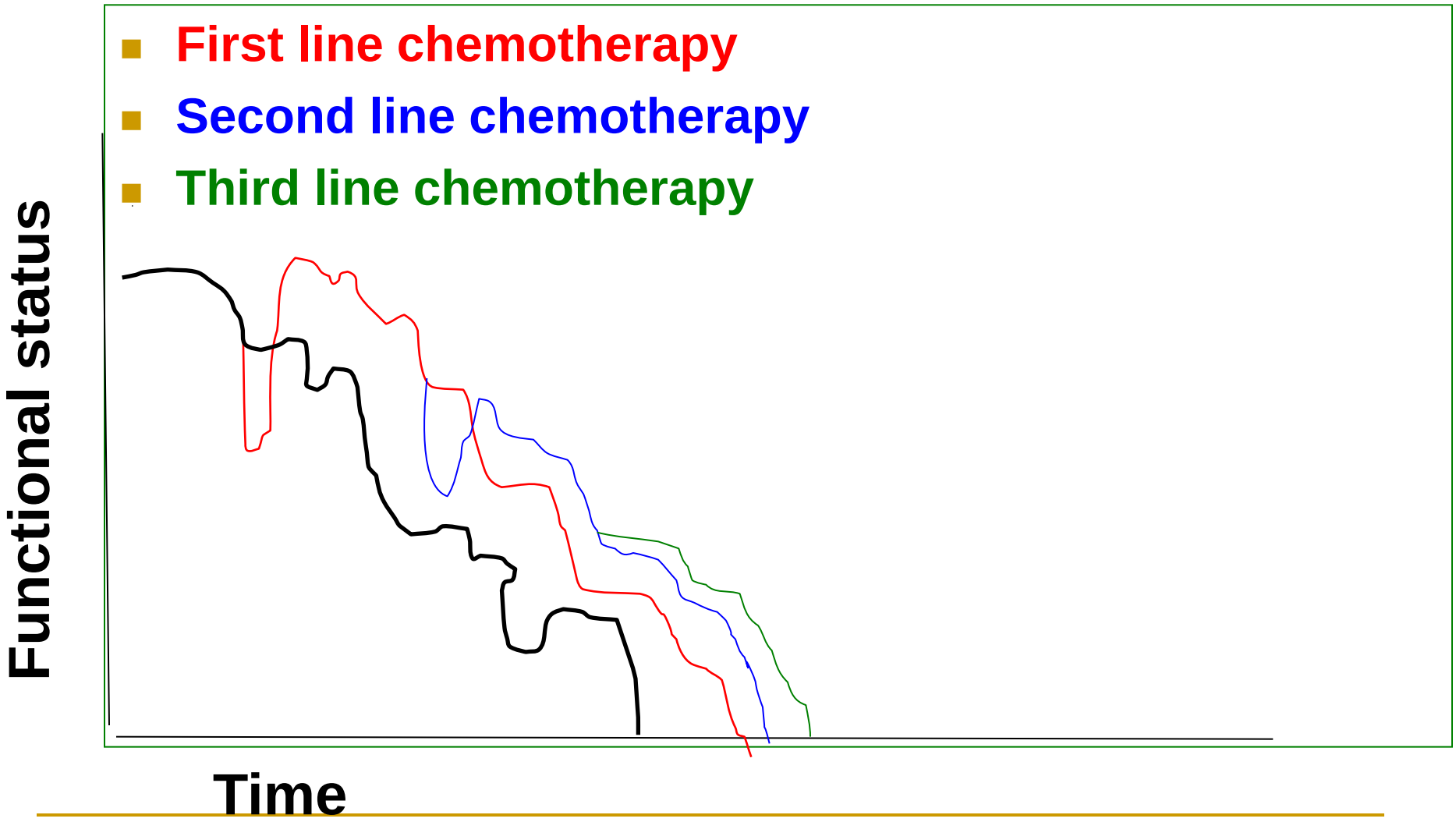
- Patients, if able, their families and the medical team caring for the patient need to determine what types of treatment are warranted in light of stage of illness, patient's quality of life and values.
- To make these decisions, they need to consider what will happen to the patient if they get the medical treatment, now and in the future.

Metastatic lung cancer

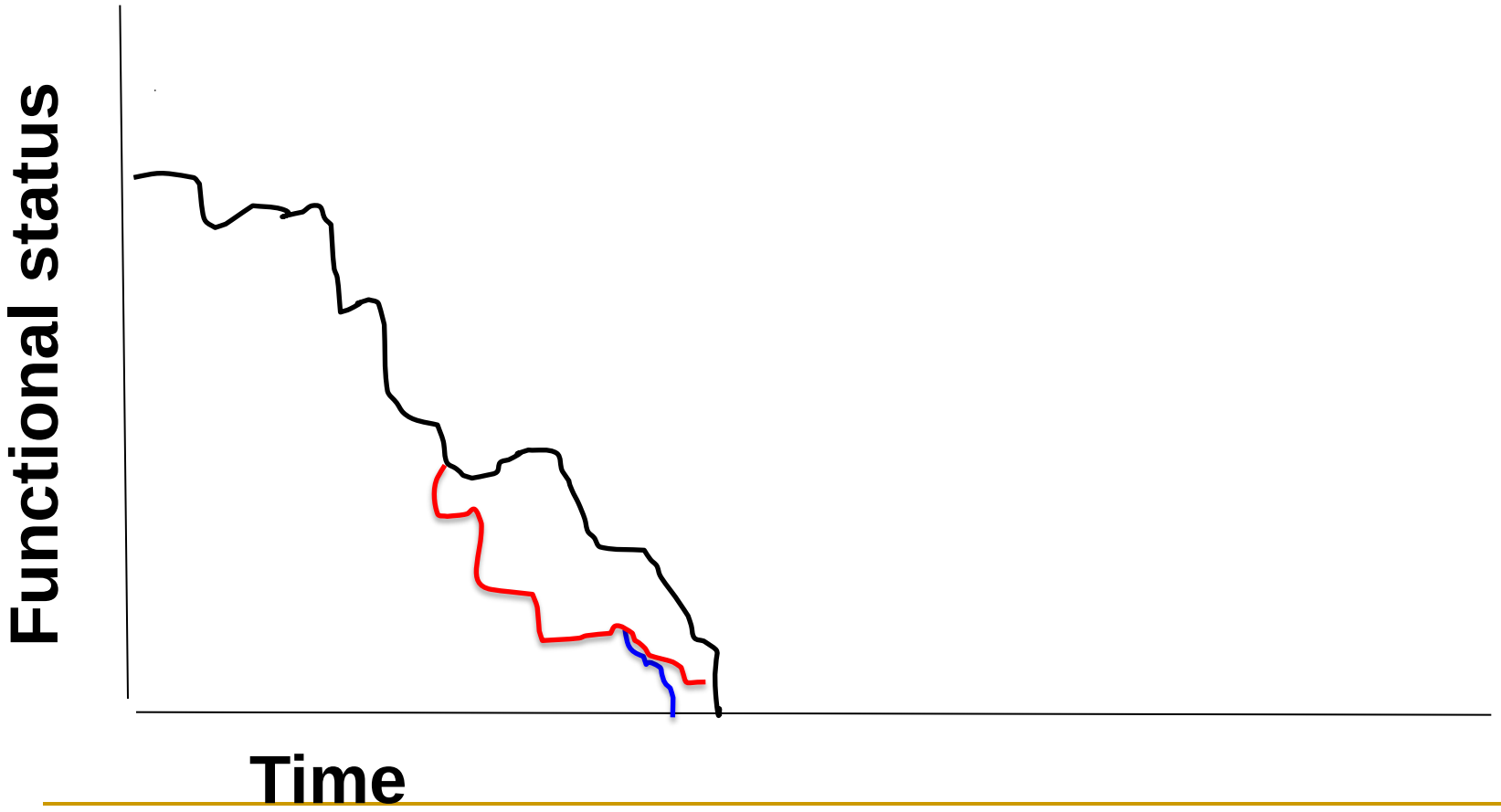


Metastatic lung cancer: what we wish treatment could do

Metastatic lung cancer, what treatment can do



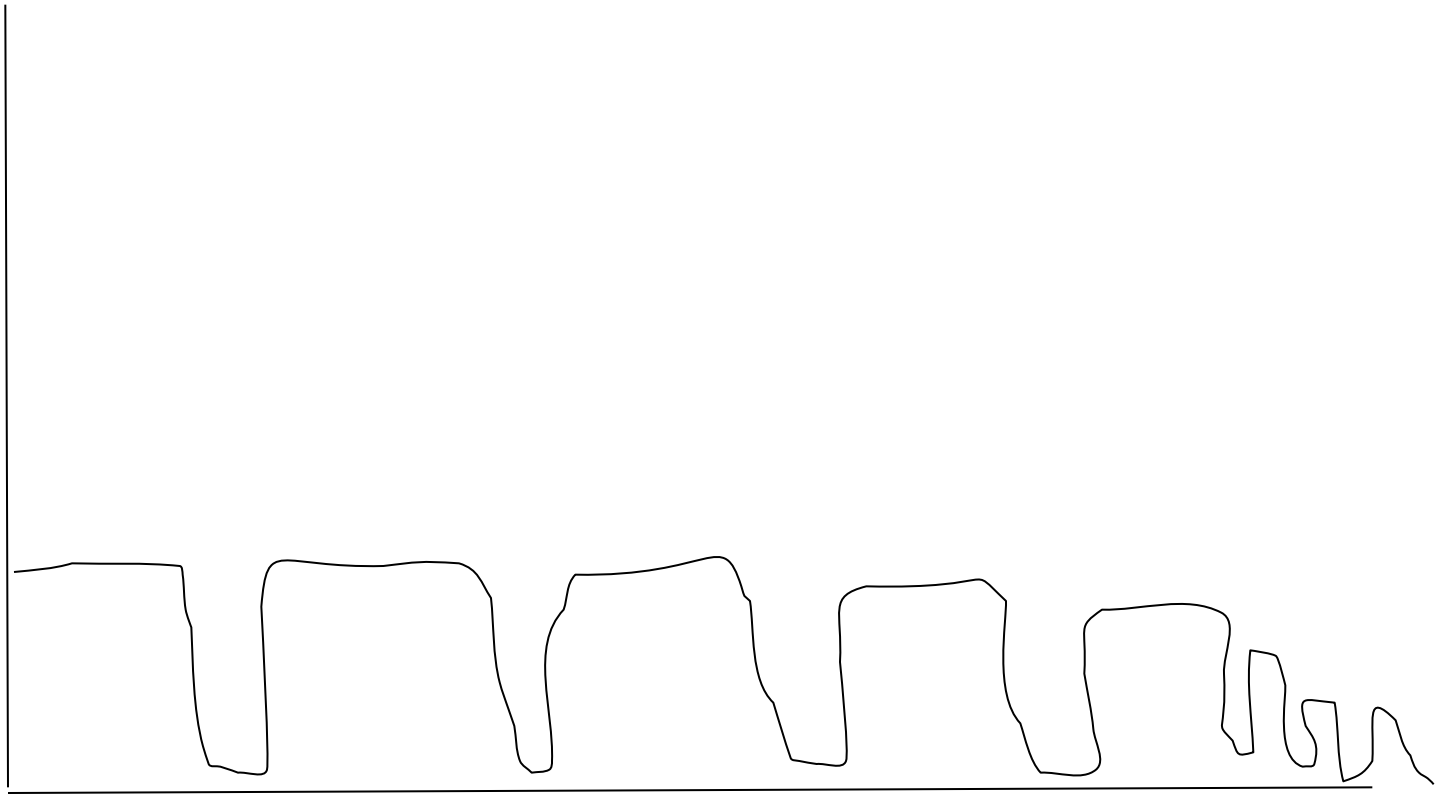
Metastatic lung cancer: what treatment can also do



Metastatic lung cancer: treatment decisions

- Do you do first line chemotherapy?
- Second line chemotherapy?
- Third or fourth line?
- What about CPR, or mechanical ventilation?

End stage congestive heart failure



Cardiac disease and end of life care

- Treatments that prolong life, often improve functional status and quality of life as well!
- Harder to predict mortality than cancer or other illnesses.

Cardiac disease and end of life care

- Several interventions (implantable defibrillators, pacemakers) prevent sudden death from arrthymias, and prolong life.

Goals of care

- These devices do not cure CHF, and can not prevent eventual functional deterioration.
- If patient's functional status has deteriorated to the point where they would no longer want it prolonged, what do we do with these devices?

Palliative care, hospice and choices at the end of life

- While patients and families often feel that they have to chose between quality of life (“comfort”) and life prolonging treatment, this is not always so.
- Several recent studies show that patients with cancer and other life limiting illnesses (such as congestive heart failure) live longer when receiving palliative care or hospice.
- This is probably because improving symptoms such as pain improves functional status thereby increasing life expectacy.

Other choices

- Patient with permanent alteration in functional status have a different illness trajectory. These patients have have an injury or illness which places them in a functional state which is severely reduced, without having progressive symptoms.
- Traumatic brain injuries or strokes which lead to permanently altered mental status or even vegetative states are one example of such illnesses.
- These are illnesses in which life could be maintained for prolonged period of time, but the quality of life is such that many would not want their life prolonged.

What can medicine do when it can't save your life?

- Prolonging life where possible *and desirable.*
- Improving the quality of life (treatment of symptoms such as pain, dyspnea, nausea, depression, fatigue.
- Supporting families.
- Working with patients and families to figure out goals of care at different stages of life-limiting and terminal illness.

This is not a job for you

- End of life care needs to involve an interdisciplinary team (physicians,nurses, aides, social workers and chaplains).
- It is patient and family centered.

Mindfulness

Don’t just do something, sit there.

As the great moral philosophers of our time say:

- You can’t always get what you want, but if you try sometimes you get what you need.


DEATH?
SPEAKING.
THIS IS THE BOSS. WHERE ARE YOU? YOU HAVEN'T BEEN TO THE OFFICE IN DAYS!
I'VE BEEN HELD UP.
WHAT HAPPENED?
YOU KNOW HOW WHEN SOMEONE DIES, THEY CAN CHALLENGE ME TO A GAME FOR THEIR SOUL?
SURE, STANDARD PROCEDURE.
WELL, WE DIDN'T COUNT ON THIS GUY. I MIGHT BE A WHILE.
I ADD THE PALADIN TO MY PARTY.
OH, JESUS. HE'S GETTING OUT ANOTHER RULEBOOK.