



Malaysian
Hospice &
Palliative Care
Council

Caring Together



National
Cancer
Society
Malaysia

Giving Hope Celebrating Life

THE NATIONAL CANCER SOCIETY OF MALAYSIA SARAWAK BRANCH



KEMENTERIAN KESIHATAN MALAYSIA

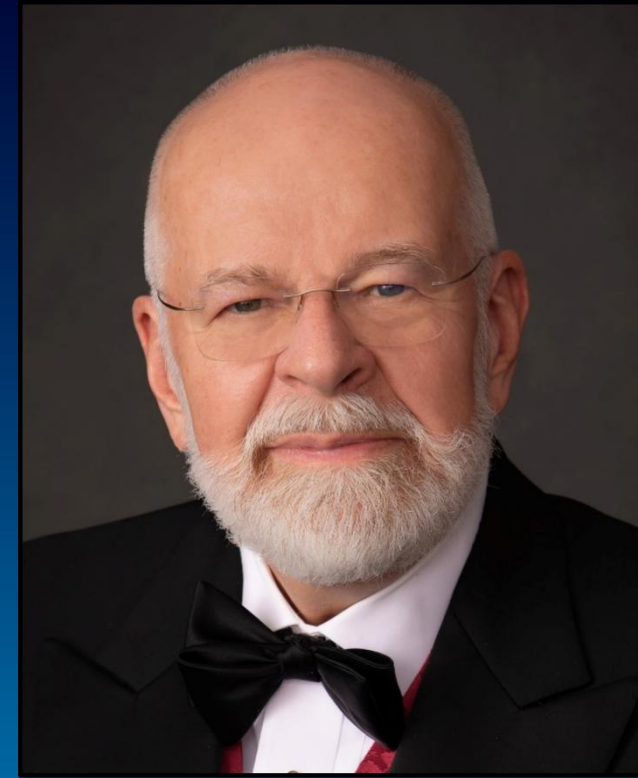


Upstream Palliative Care Opportunities & Challenges



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Nothing to Declare
You can adapt and use
our presentations with attribution

Success of Modern Medicine...

Penicillin – First Antibiotic

- Discovered in London by Alexander Fleming 1928
- First used to treat pneumonia in people 1942
- First available to general public in USA 1945

The Evolution of Oncology Care

Late 1940s – 50's

75 years

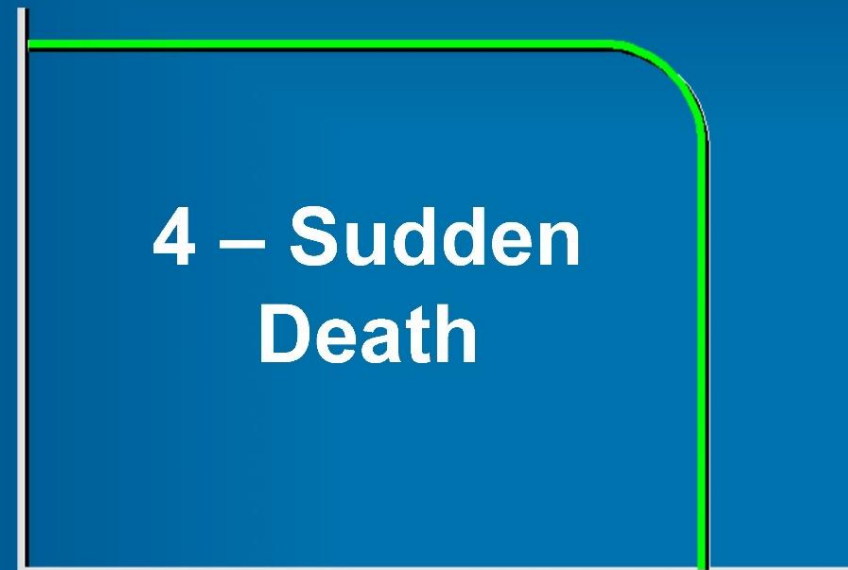
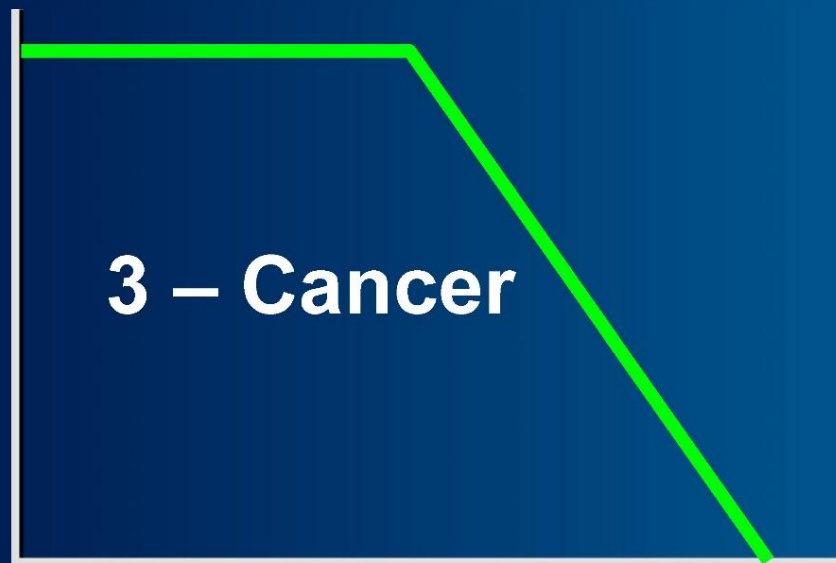


2020s

- Nitrogen mustard
- Folic acid
- Cyclophosphamide
- Methotrexate
- Cobalt XRT
- Compazine & chlorpromazine for nausea

- Complex chemotherapy
- Immunotherapy
Car T cell
- Linear accelerators
- Gamma knife

Patterns of Functional Decline



Multiple Issues Cause Patients & Families Suffering

Disease Management

- Diagnosis
- Prognosis
- Management

Physical

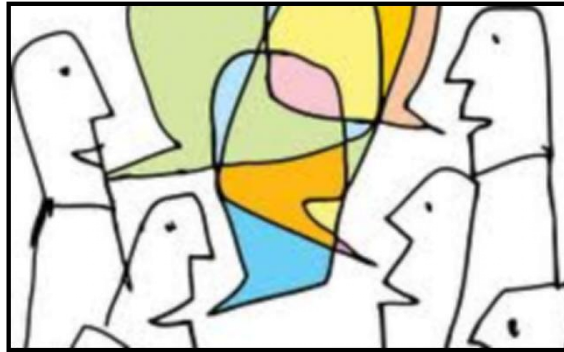
- Pain, shortness of breath & other symptoms
- Function, fluids, nutrition

Psychological

- Anxiety
- Depression
- Distress

Loss, grief

- Emotional responses
- Bereavement



Social

- Family dynamics
- Financial
- Legal

End of life / death management

- Last hours of living
- When death occurs

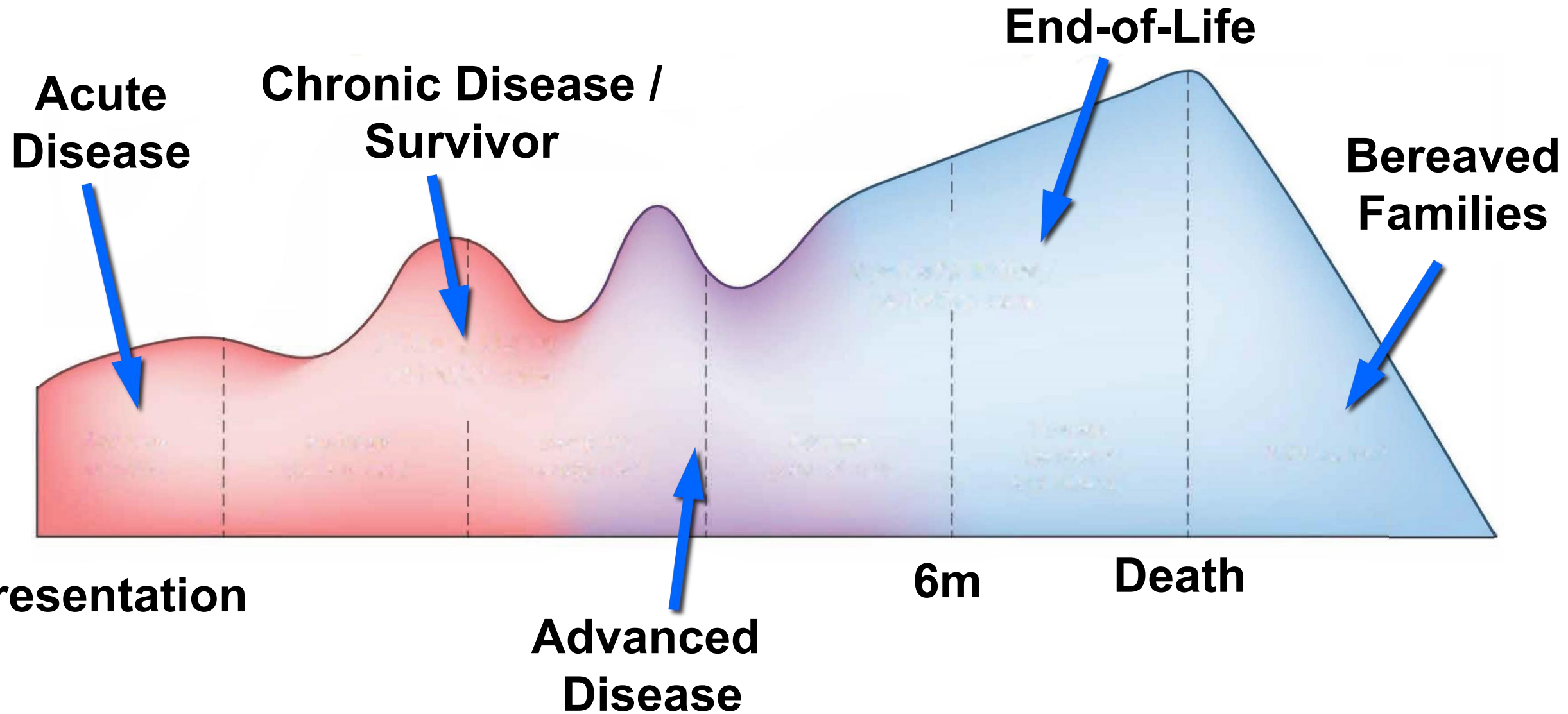
Practical

- Caregiving
- Teamwork
- Volunteers

Spiritual

- Hope
- Meaning, value
- Existential

Modern Illness Experience



Palliative Care is...

New Knowledge & Skills to Manage the Experience of Patients & Families...

- Prevent & relieve suffering
- Promote quality of life, death & bereavement
 - Any diagnosis
 - Any time there is need

Adapted From: Ferris FD et al. A Model to Guide Hospice Palliative Care,
2002. <https://bit.ly/2UQyO7q>

What does
Upstream Palliative Care
mean to you ?

Case : Ellen Rudy

Evaluated by Charles von Gunten, MD, PhD
VP Hospice & Palliative Medicine, OhioHealth

- 81 yo Retired Nurse
 - Nursing School Dean for 10 years
 - “ Talks Fast and Walks Fast ”
- Married, 3 sons
- Pulmonary Fibrosis
- Very short of breath
- Sleeping 18 hours each day
- Significant weight loss



Prognosis
2 – 4 weeks

**Without Palliative Care
How will she end her life...?**

With Expert Palliative Care...



Morphine 5 mg PO Q1H PRN !

“ Makes me Ellen Again ”

**Ellen was able to get up out of bed
Sleep normally... 7 – 9 hours per night**

She gained weight...

She was able to live !

**In the last 2 weeks of her life,
Ellen became intolerably short of breath...**

**Lorazepam 2 mg buccal mucosa Q12H &
1 – 2 mg buccal mucosa Q1H PRN
kept her comfortable while she died**

Does Ellen's Outcome Surprise you... ?

She lived another **18 months**
“ walking and talking fast ” ...

She died peacefully at home
(Original prognosis 2 – 4 weeks)

**What would Ellen's life have been if
she received Morphine PRN
much earlier...?**

Goals of Palliative Care

Help Patients

- Eat well → Live better
- Sleep well → Be themselves
- Maintain function → ↑ Prognosis
- Reduce stress

Upstreaming Strategies

Opportunities & Challenges...

Upping Our Game

- **Be competent to provide the best to care**
 - Pathophysiology**
 - Pharmacokinetics**
 - Skilled nursing & counselling**
 - Effective bereavement**
- **↑ Hospice & Palliative Medicine Specialists**

Knowledge & Skills Upstream

- All primary providers have
core palliative care knowledge & skills
- Education for
 - Medical students, residents, practicing physicians
 - Nursing students, advance practice nurses
 - Counsellors
 - Volunteers

Hesitancy Addressed

- **Confident modeling to address clinician, patient, family, and caregiver hesitancy**
- **Skilled**
 - Communication**
 - Symptom management expertise**

Access When Needed

- **Patient and family have access EARLY in the illness, whenever needed**
 - “ Triggers ” help identify patients needing a consult
- **Palliative care consult services available & responsive**
 - Practice consultation etiquette
- **Outpatient clinics are embedded in disease management clinics**
 - Oncology, cardiology, pulmonology, geriatrics, etc.

Value Understood

- **Well established relationships**
 - Many in your circle of influence
- **By clinicians**
 - Help their patients live longer & better
 - Deal with complex & challenging patients & families
- **By administrators & funders**
 - Financial advantages
 - Quality improvement
 - Patient & family satisfaction

**What can the Impact
of Providing Palliative Care
Upstream be...**

Kit, 58 year old

- **New workplace**
- **Pre-employment health screen**
- **Large peripheral lung mass on chest x-ray**



Every Encounter . . .

**FACTS / PLANNING
SHARED DECISION-MAKING**



VALIDATE EMOTIONS

BUILD TRUST

PAINS

SHAME

POWER IMBALANCE

UNCERTAINTY

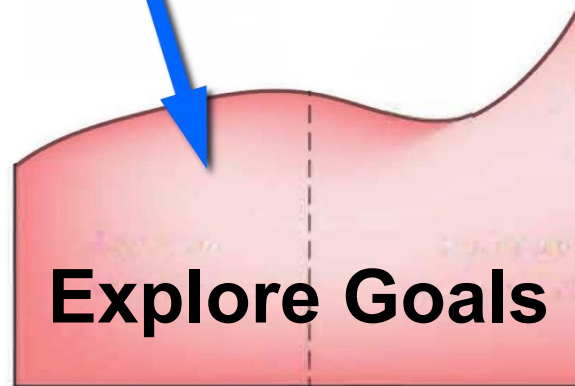
FEARS

ANXIETY

STRESSES

Modern Illness Experience

Disease
Evaluation
Surgery



Values:

Longevity

Work life

Family

Kit, 58 year old

Peripheral lung mass on routine chest x-ray

- Wants **best** treatment for her cancer
- Wants to be comfortable, with family
- Wants to continue to work / life



Initial Work-up

- Subtotal pneumonectomy
- Adenocarcinoma, primary unknown

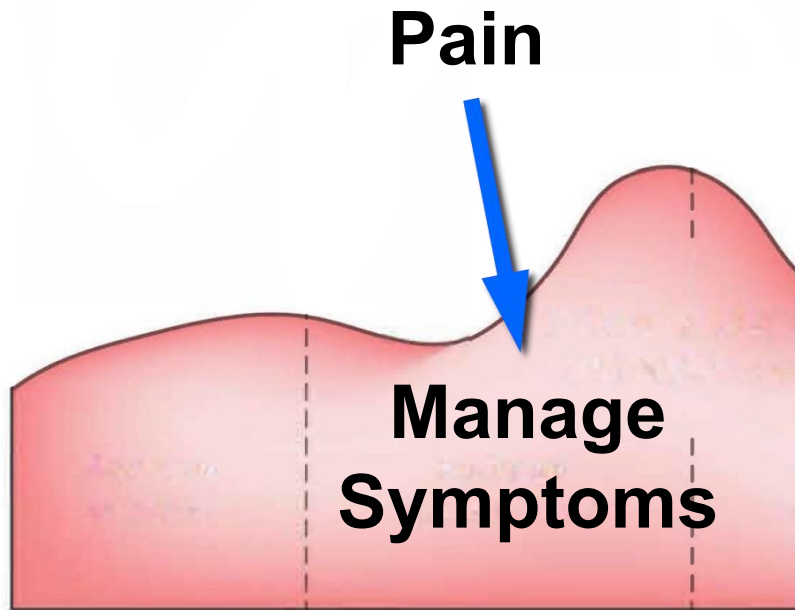
No known metastasis

Prognosis 8 – 13 months

- Post-thoracotomy pain syndrome
Opioids + adjuvants to control pain



Modern Illness Experience



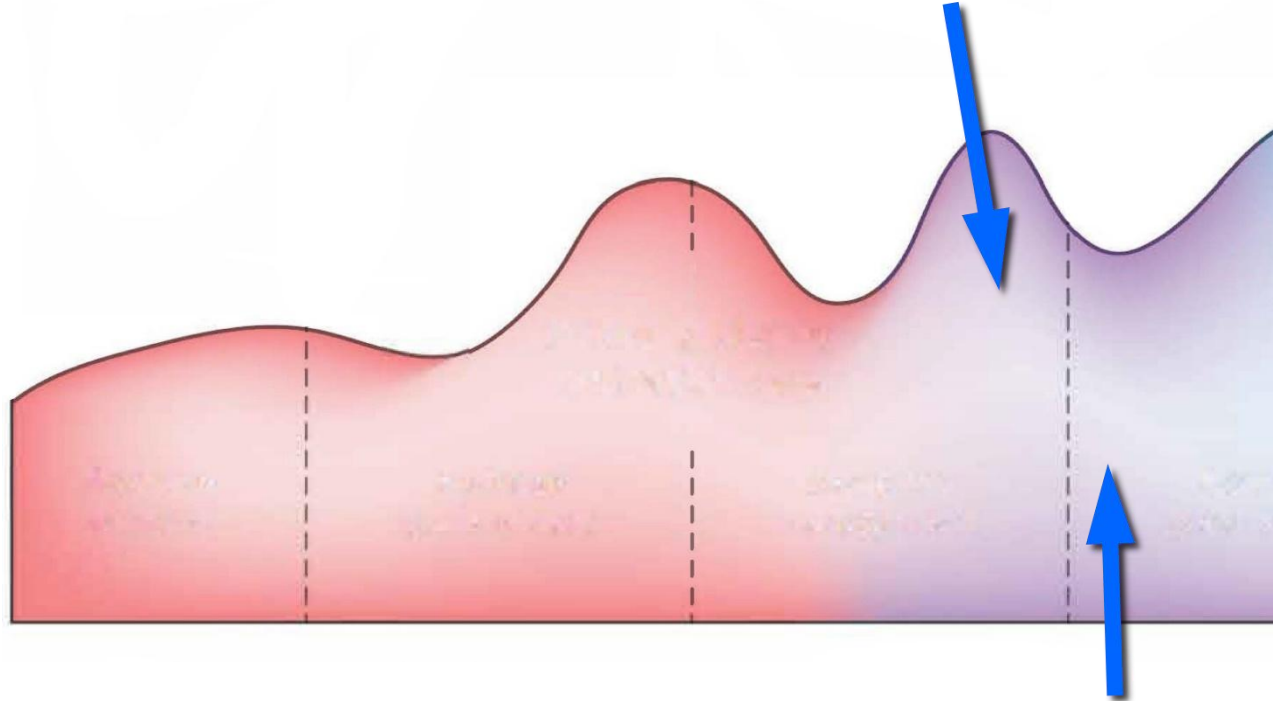
Illness Experience

- 6 month later, recurrence axillary lymph nodes
- Chemo: Carboplatin & Taxol
 - Partial response
- XRT: 6000 cGy 30 fractions
 - Partial response
- Further Chemo → stable disease
- At 21 months, Resection possible ?
Missed 1 day of work



Modern Illness Experience

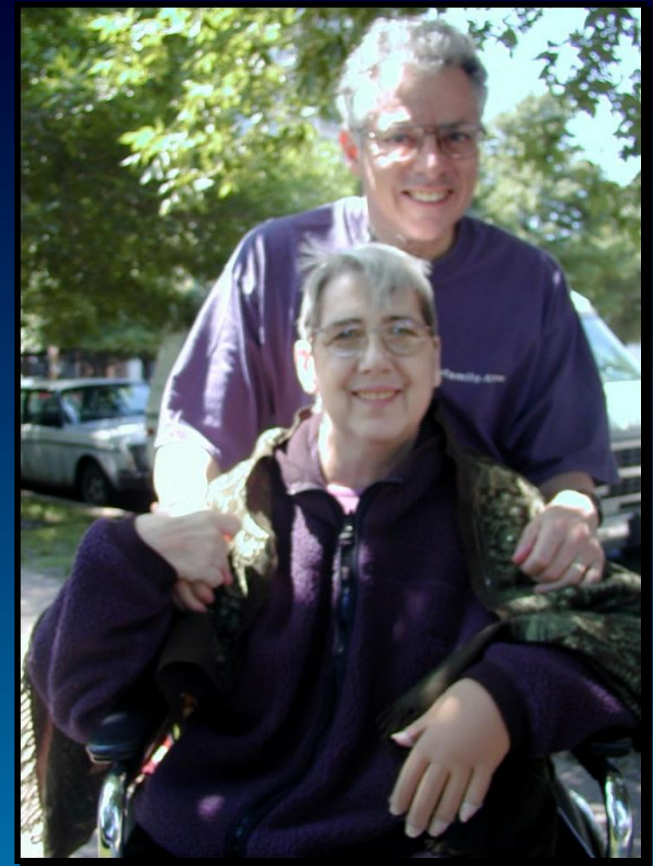
Recurrence !



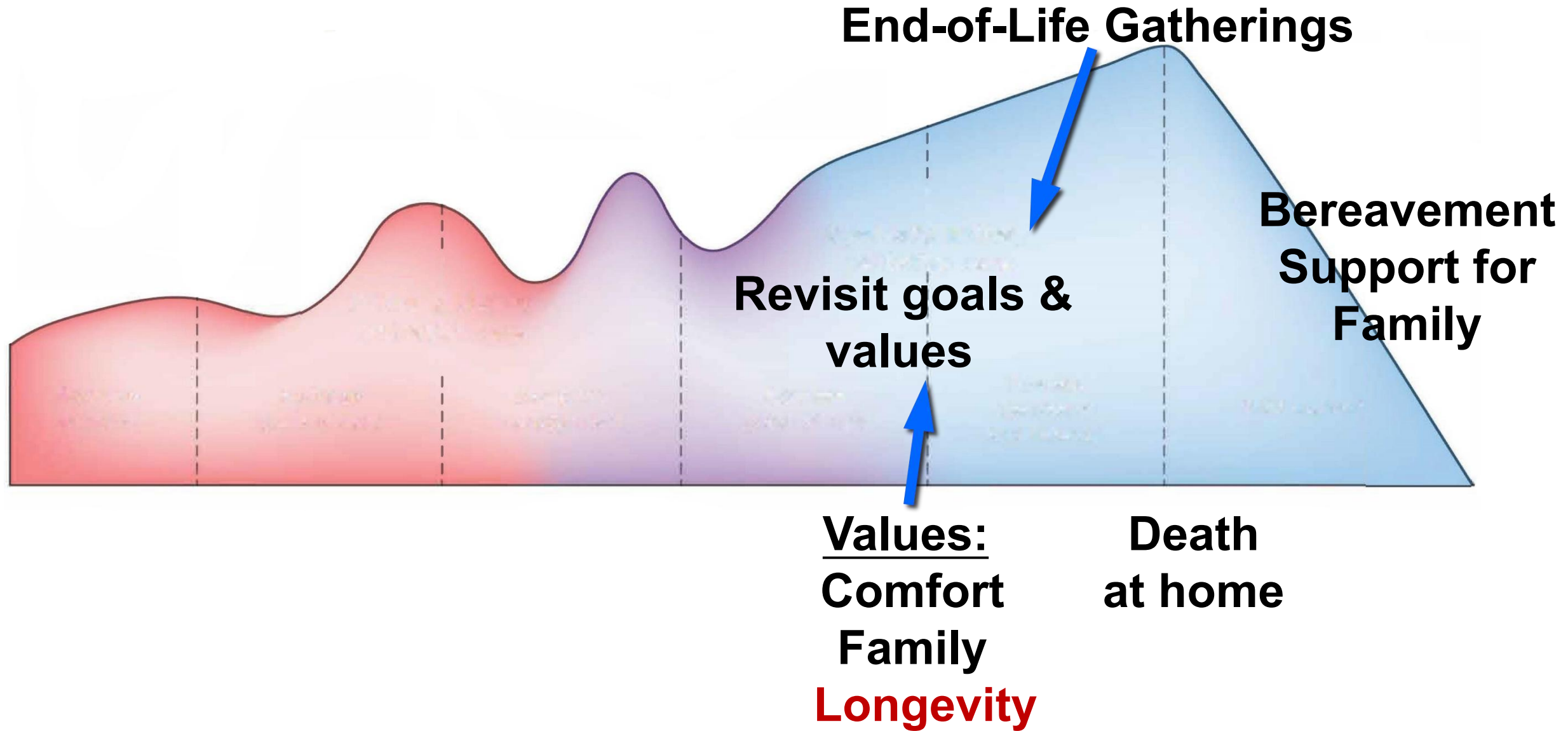
**HARD
Chemo
XRT**

At 21 Months, Changes Goals of Care

- Enrolls in Hospice Care
- Oncologist visits
- Resolution of relationships
- Gifts
- Surprises
- Died at home 24 months
after her diagnosis
(Projected 8 - 13 months)



Modern Illness Experience



Why Kit's Story was So Successful...

- Oncology & Palliative care offered in setting of trust
- Expert communication & exploration of goals & values
- Targeted treatment based on Kit's goals & values
- With progression, Kit's goals & values were revisited
- As Kit's goals & values changed, treatment plan changed



**Kit had a high-quality longer life
that was meaningful to her in every way**

Access to Palliative Care Upstream
can ↑ Experience, ↑ Survival,
and may ↑ Effectiveness
of Anti-disease therapies

It's About Building Trust & Building Relationships



What are you
going to do
on Tuesday...?