Paediatric Palliative Care

- From Oncologist Perspective

Dr Rever Li
HKSCPC Annual Symposium
23 March 2019

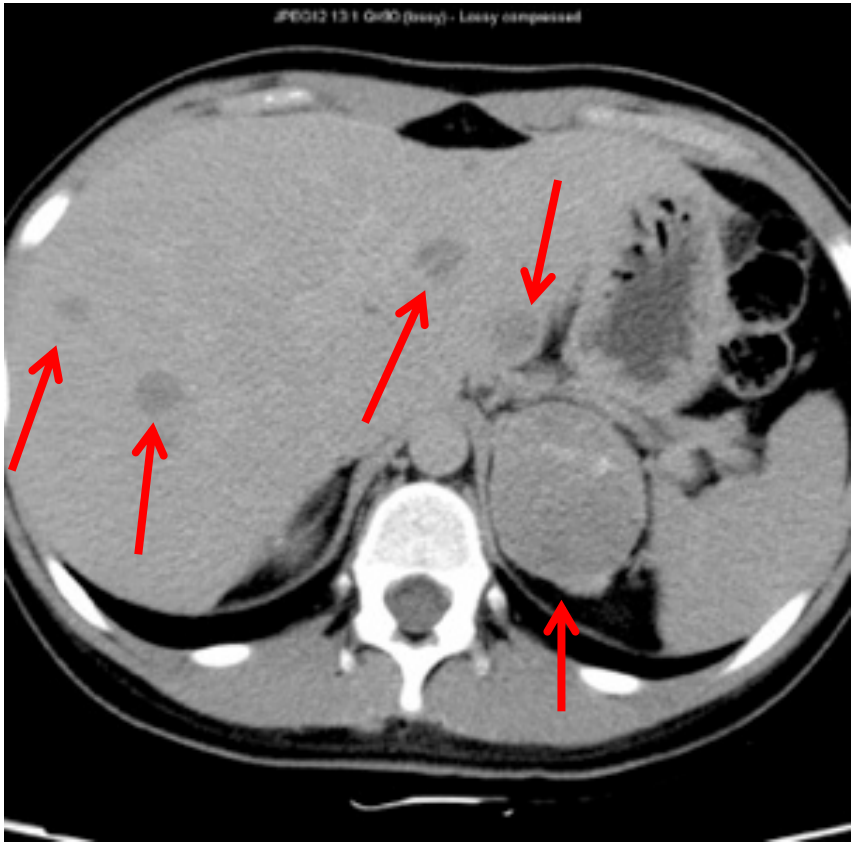
- Case sharing

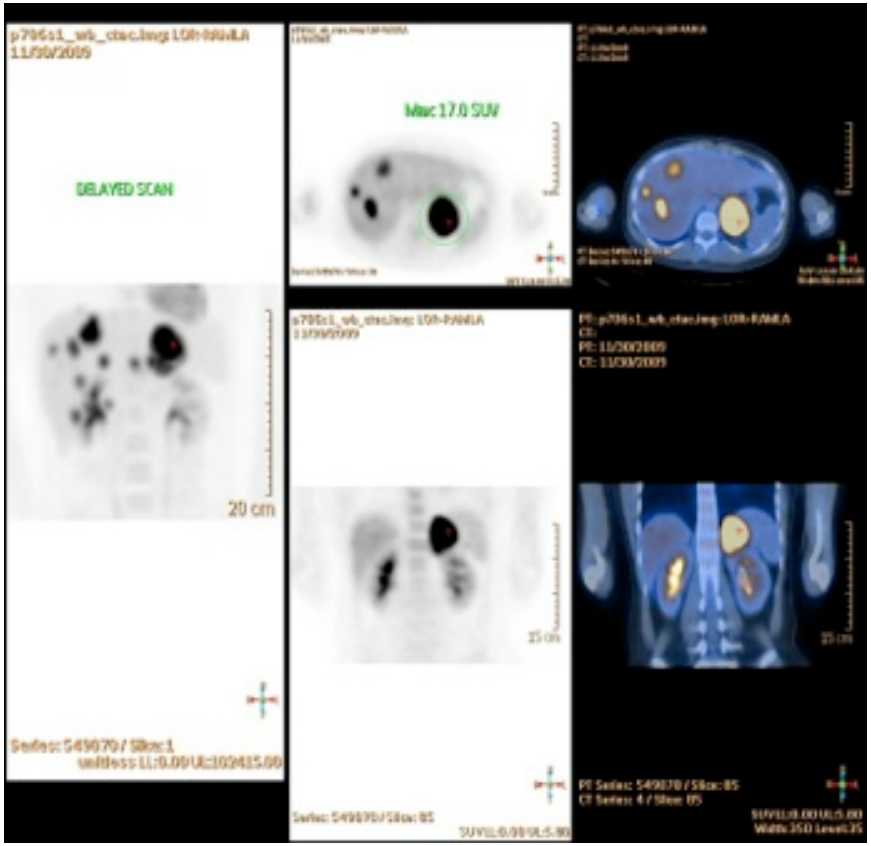
- Paediatric Palliative Oncology:
  - When to initial palliative care ?
  - Good Communication
    - how & when to involve children and adolescent in discussion
  - Good symptom control
  - Good EOL care and bereavement support

Story of Lily….

- Lily, 15 yr old girl
- Presented with obesity, hirsutism and amenorrhoea
- Blood tests: abnormal cortisol hormone profile
- CT & PET scan: large tumour in left adrenal gland, multiple metastasis in liver
- **Adrenocortical carcinoma (Stage IV disease)**

CT and PET scan



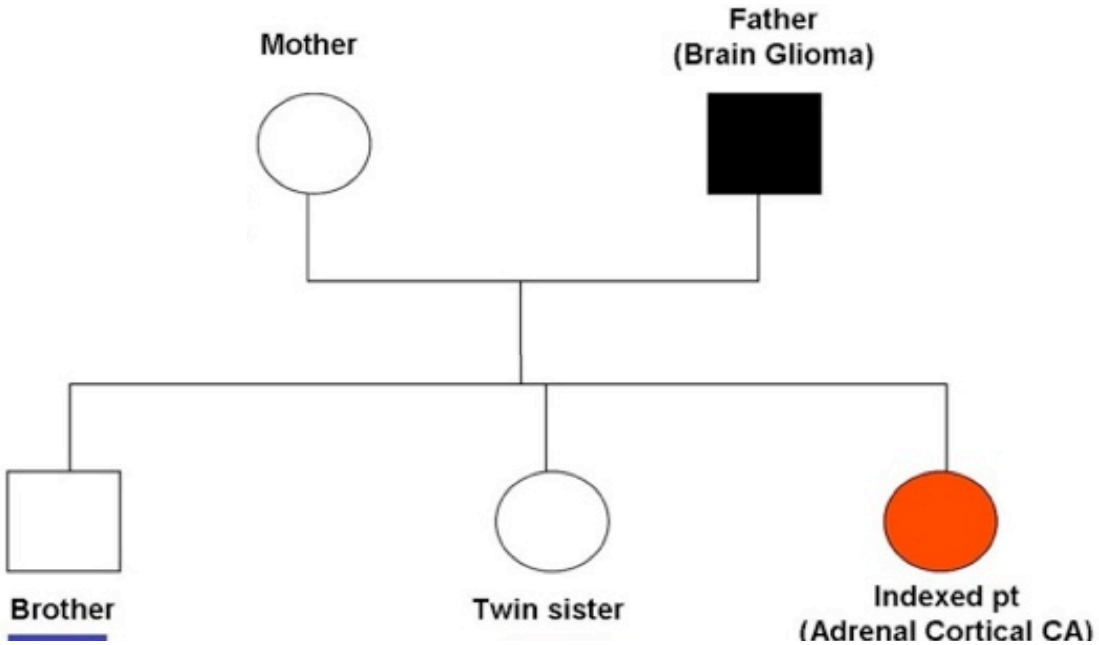


A large heterogenous mass in left adrenal gland
Multiple liver metastasis

Story of Lily

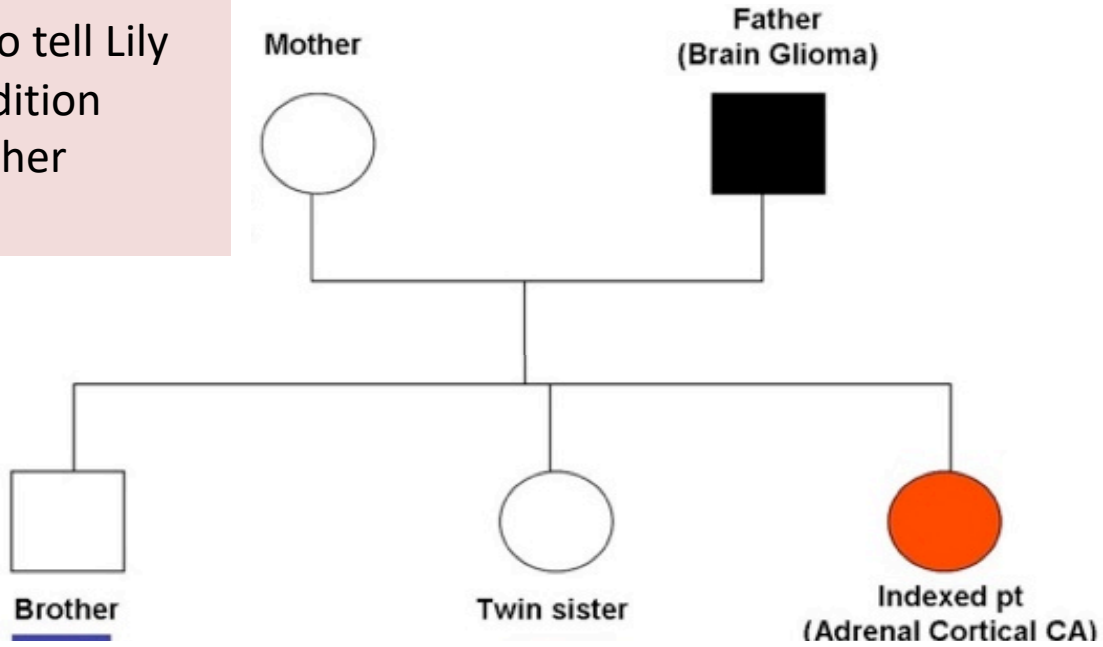
- Surgical excision impossible
- Tumour resistant to radiotherapy
- Commenced on chemotherapy
- FU PET scan: Increase size of tumour in adrenal gland and liver, new lesion in vertebral bone
- Chemotherapy stopped
- Trial of Sorafenib (TK inhibitor), no response

The Family

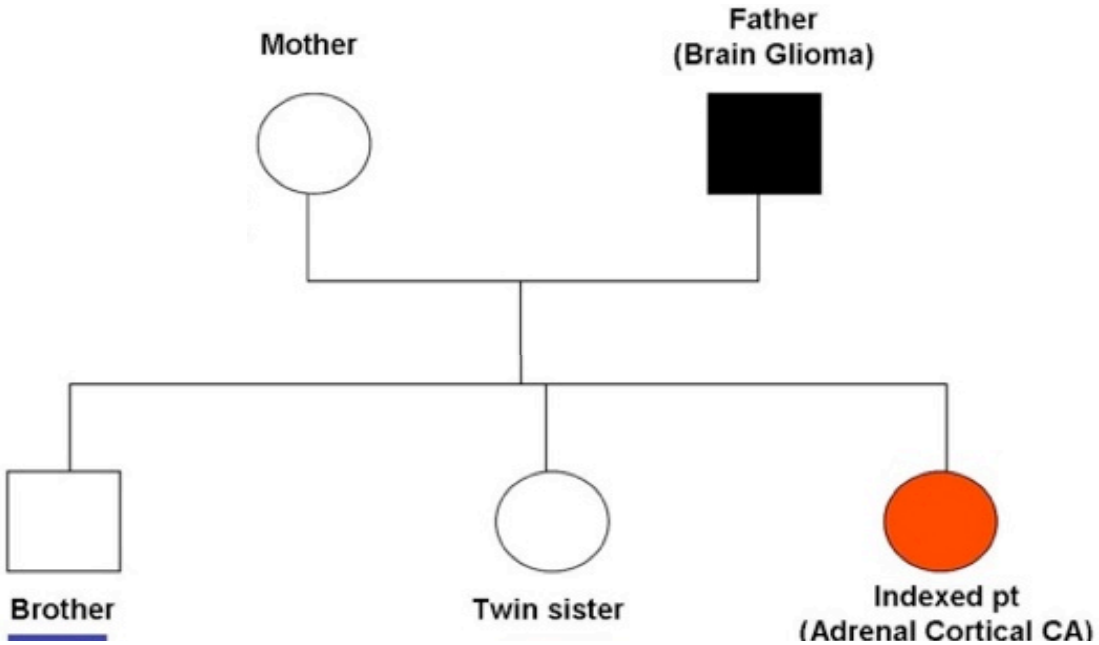

Mother
Father
(Brain Glioma)
Brother
Twin sister
Indexed pt
(Adrenal Cortical CA)

The Family

Mother still in the grief of the death of husband
Requested not to tell Lily the disease condition
Demand for further treatment

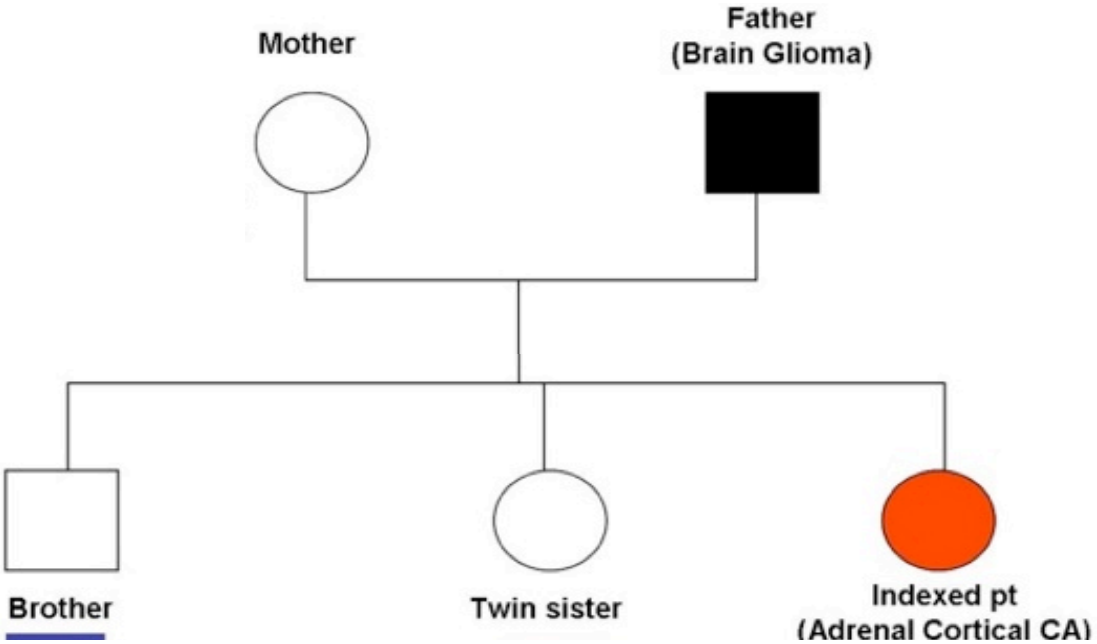


The Family



Fear of having the same cancer

The Family



being the only male in the family shoulder the expectation of looking after mother and younger sisters

Lily….

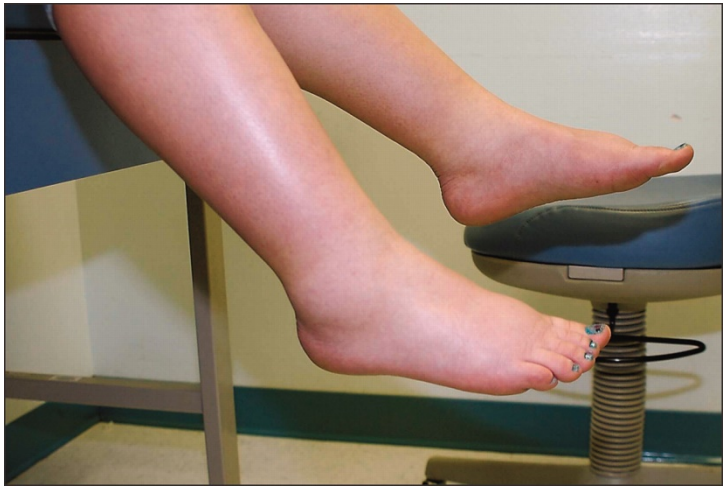
- Lily was smart and mature
- She insisted to join the interview with medical staff
- She was informed about the diagnosis, the unfavorable treatment response, stopping chemo as not helpful

Clinical symptoms

- Abnormal hormone profile:
  - Hypertension: Nifedipine
  - Hypokalaemia: Spironolactone
  - Moon face, hirsutism, acnes: Metyrapone
- Pain:
  - Abdomen pain: tumour distension in liver and adrenal
  - Bone pain: bone metastasis
  - *Syrup morphine, MST, Methadone*
  - *Fentanyl patch*
  - Morphine induced pruritus, nausea, constipation, drowsiness

Clinical symptoms

- Progressive leg edema due to tumour compression in IVC
- Pain, unable to walk, thinning of skin, leaking of serous fluid
- Inserted an ***stent*** into the IVC by radiologist
- Relieve pain



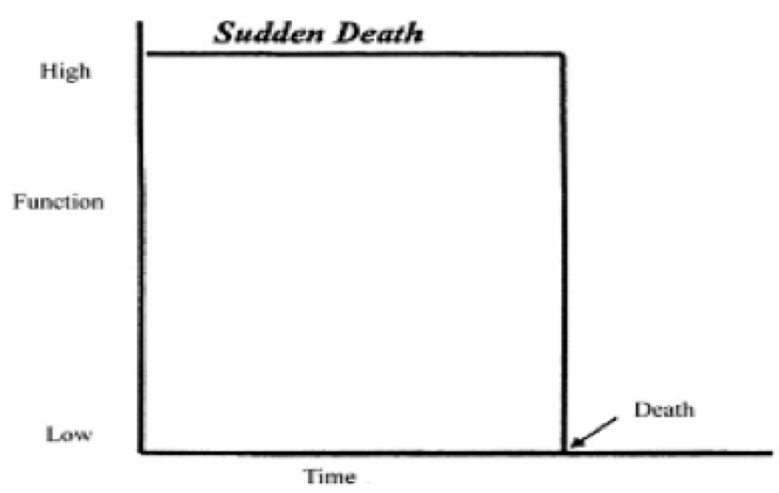
Last wish of Lily

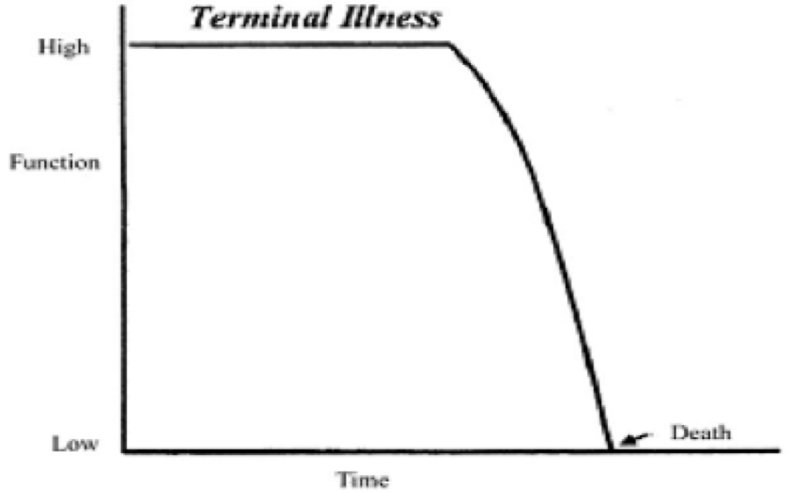
- Farewell party with her family, teachers, friends, medical staffs

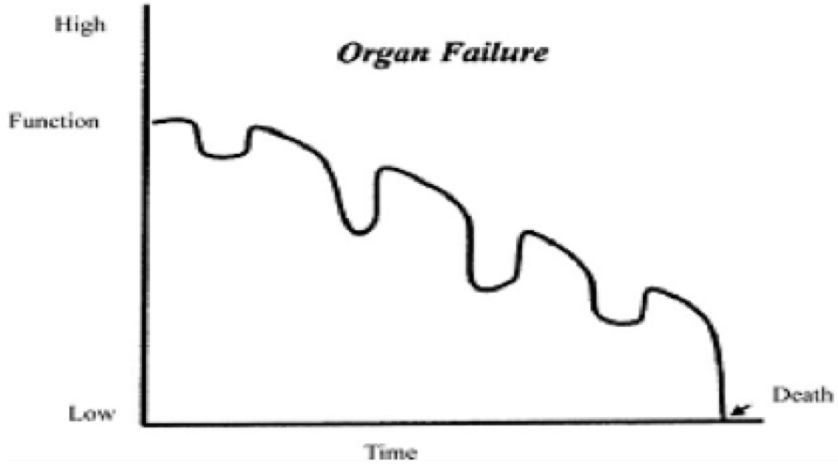
Last admission…

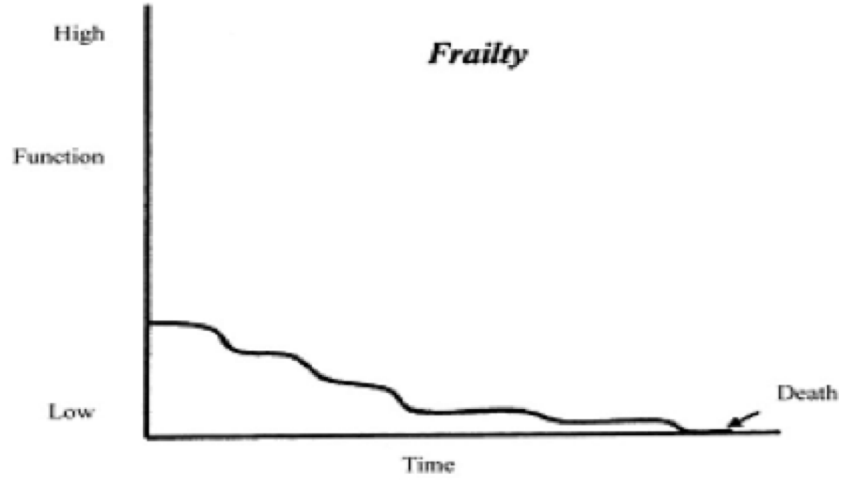
- High dose of IV morphine
- Irritable, distressful
- Progressive dyspnoea
  - SpO2: 95% in O2 2L/min
- Fear of dying and panic anxiety
- Passed away in the presence of mother and siblings

Proposed Trajectories of Dying









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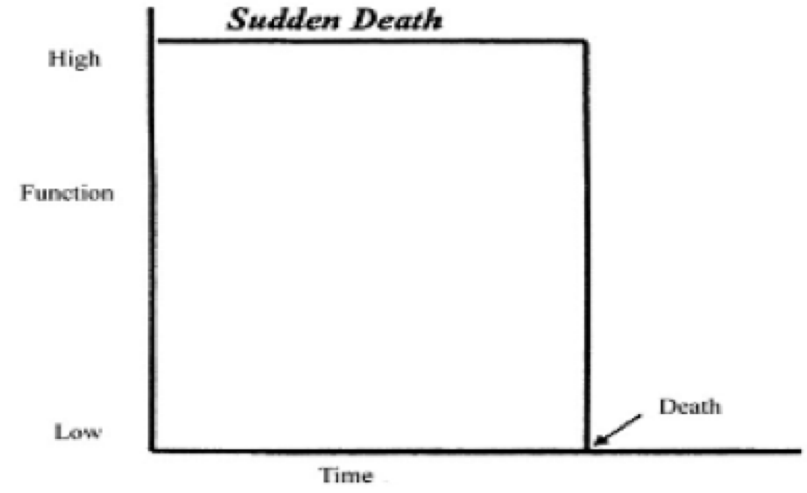
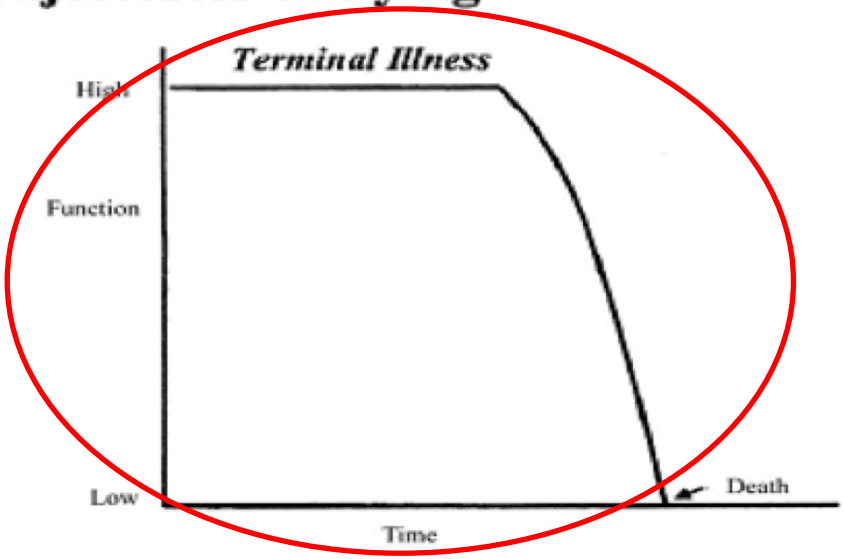
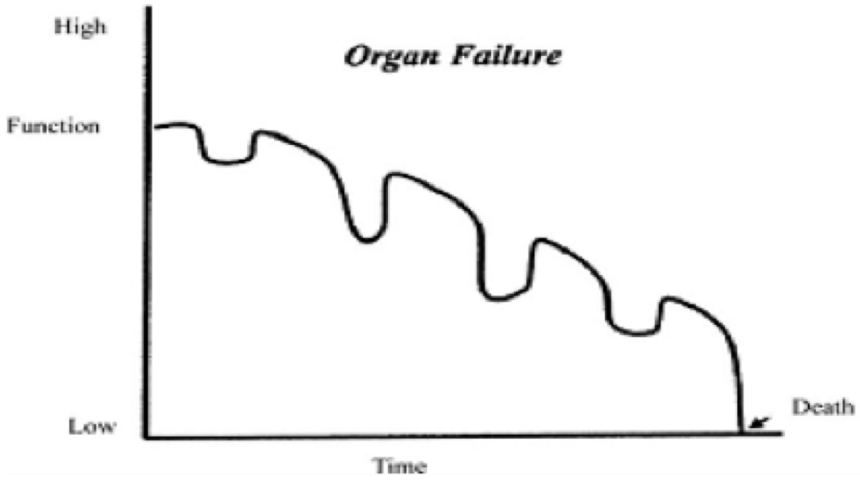
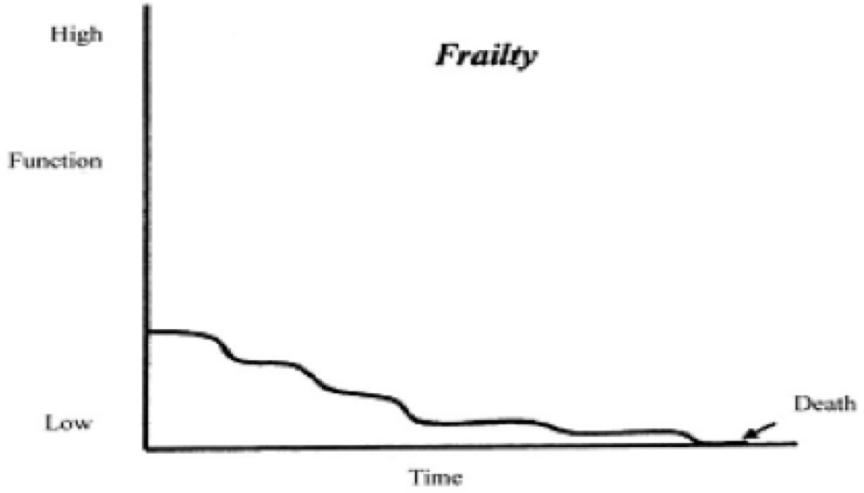








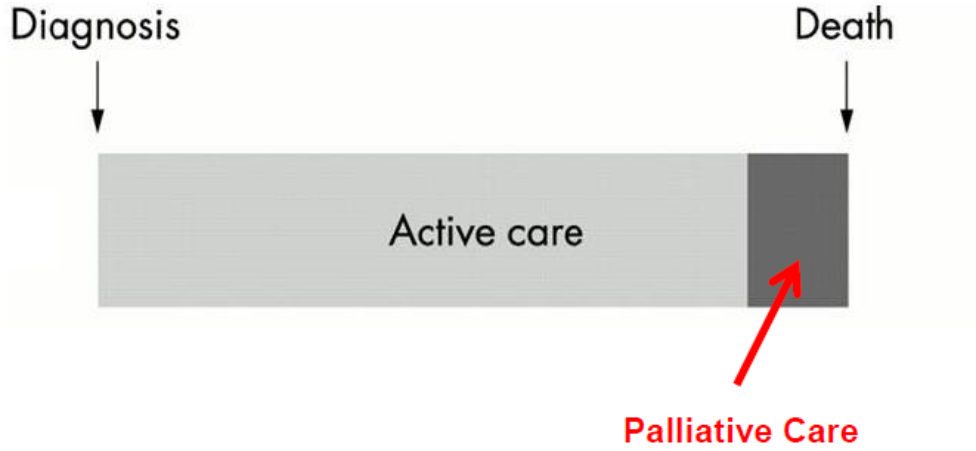
Paediatric Oncology

- Continue advances in paediatric oncology
- ***Overall cure rate: 80%***
- ***HK 2018: children cancer new cases: 181, death: 27***
- Some cancer types, eg. Acute Lymphoblastic Leukaemia, very favorable outcome with cure rate >90%
- Emerging new technology and treatment, eg. target therapy, immuno-therapy, cell-therapy, HSCT
- Shift the treatment paradigm of certain cancer from an acute, cure-based therapy to a model for management of chronic disease

Snaman . Curr Opin Ped 2018

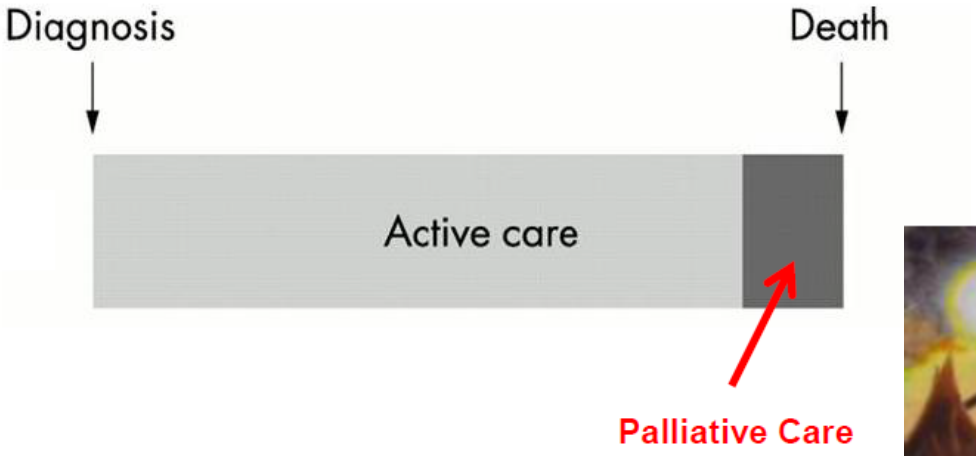
When to initiate PPC?

Perceptions of Palliative Care



When to initiate PPC?

Perceptions of Palliative Care



Fluctuating clinical course

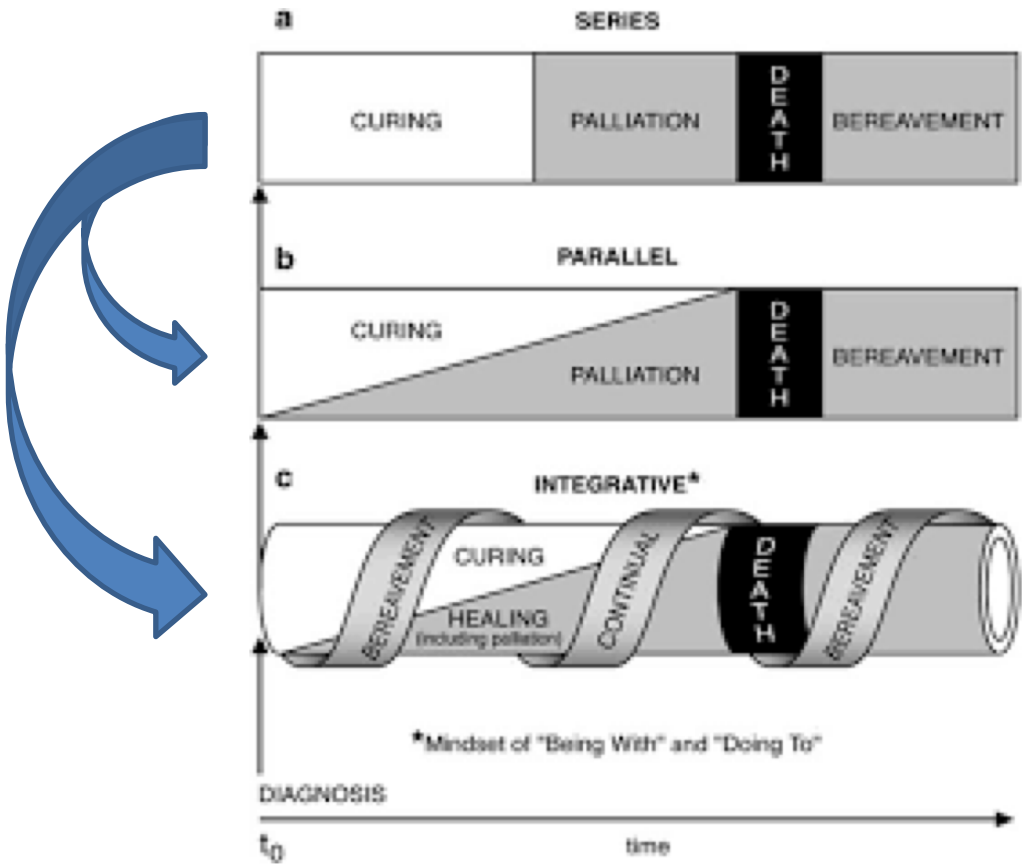
When to initiate PPC?

- When is it right to “let go”?
  - *try the 2nd, 3rd, 4th line of treatment??*
- Who should let go first?
  - *Clinicians?*
  - *Family ?*
- If you let go too early people can be hurt
- If you hang on too long people can be hurt

What Palliative care actually offer?

Communication	• Shared decision making • Advance care plan, goal of care • DNACPR
Symptom control	• Pain • Nausea and vomiting • Respiratory symptom • Psychological symptom
End-of-life care Bereave care	• Manage End-of-life symptom • Communication • Bereavement support

When to initiate PPC?



Will it be too early to initiate good communication?
Will it be too early for good pain & symptom control?

When to initiate PPC?

Early Integration of PPC

- Wolfe et al. *J Clin Onc*. 2008.
  - Retrospective comparison of pediatric oncology pts who died at BCH between 1990-1997 & 1997-2004
  - In the f/u cohort (after PACT):
    - More frequent (76% vs 54%) and earlier (52d vs 28d prior to death) conversations about hospice
    - Earlier documentation of DNR (18d vs 12d PTD)
    - Parent report of ↓suffering from pain (RD of 19%) and dyspnea (RD of 21%)
    - Larger proportion feeling more prepared during last month (RD of 29%) and at time of death (RD of 24%)

CURRENT OPINION

Pediatric palliative oncology: the state of the science and art of caring for children with cancer

Jennifer M. Snaman[a,b], *Erica C. Kaye*[c], *Justin N. Baker*[c], *and Joanne Wolfe*[a,b]

Pediatr Blood Cancer 2016;63:583–584

HIGHLIGHT

Joanne Hilden, MD*

It is Time to Let in Pediatric Palliative Care

In this issue of *Pediatric Blood & Cancer*, Kaye et al. present a timely review of the field of pediatric palliative care (PPC).[1] They start with a review of the literature showing the value to

family is not ready." When the care team is approached, we hear "they are not ready." Or even worse, "we are not allowed to talk about palliative care in that room."

→Early Integration of PC to children with high risk cancer

Communication

- Help parents to understand the situation
- Listen what they need or want
- Allow them to prepare
- Clarify goal of care – Advance Care Plan
- Help them to prepare other family members, eg. grandparents, other children
- Help them to prepare the patient
- Be Compassionate

When and how to talk with children and adolescent about dying?

- Many parents afraid of breaking the “bad news” and talking about “death” with the child
- Left the child alone
- Result in mistrust

- Miss the chance to fulfil child’s last wish and enjoy the last days of life

Children with cancer share their views: tell the truth but leave room for hope

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Keywords
Communication, End-of-life care, Ethics, Paediatric oncology, Palliative care

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ABSTRACT

Aim: One in five children diagnosed with cancer will die from the disease. The aim of the study was to explore how children with cancer want to receive bad news about their disease, such as when no more treatment options are available.

Methods: We conducted individual interviews with ten children with cancer, aged seven to 17 years, at a single paediatric oncology unit in central Sweden. Interviews were audio-taped and analysed with systematic text condensation. Bad news was defined as information about a potentially fatal outcome, such as a disease relapse, or information that the treatment administered was no longer working and that there was no more treatment possible.

Results: All children expressed that they wanted truthful information and they did not want to be excluded from bad news regarding their illness. They wanted to be informed as positively as possible, allowing them to maintain hope, and in words that they could understand. They also wanted to receive any bad news at the same time as their parents.

Conclusion: Children with cancer want to be fully informed about their disease, but they also wanted it to be relayed as positively as possible so that they could stay hopeful.

ACTA Paed 2016

JAMA Pediatrics | Review

Ethics, Emotions, and the Skills of Talking About Progressing Disease With Terminally Ill Adolescents

A Review

Abby R. Rosenberg, MD, MS; Joanne Wolfe, MD, MPH; Lori Wiener, PhD, DCSW; Maureen Lyon, PhD; Chris Feudtner, MD, PhD, MPH

IMPORTANCE For clinicians caring for adolescent patients living with progressive, life-threatening illness, discussions regarding prognosis, goals of care, and treatment options can be extremely challenging. While clinicians should respect and help to facilitate adolescents' emerging autonomy, they often must also work with parents' wishes to protect patients from the emotional distress of hearing bad news.

OBSERVATIONS We reviewed the ethical justifications for and against truth-telling, and we considered the published ethical and practice guidance, as well as the perspectives of patients, parents, and clinicians involved in these cases. We also explored particular challenges with respect to the cultural context, timing, and content of conversations at the end of adolescents' lives. In most cases, clinicians should gently but persistently engage adolescents directly in conversations about their disease prognosis and corresponding hopes, worries, and goals. These conversations need to occur multiple times, allowing significant time in each discussion for exploration of patient and family values. While truth-telling does not cause the types of harm that parents and clinicians may fear, discussing this kind of difficult news is almost always emotionally distressing. We suggest some "phrases that help" when clinicians strive to deepen understanding and facilitate difficult conversations with adolescents, parents, and other family members.

JAMA Ped 2016

How to talk about dying?

- High quality of communication
- Use the language the child understand
- “Having a say, as I need at this time”

Symptom control

- *Canadian study: Kassam. J Clin Oncol 2017*
  - Paediatric oncology PC patients (40%) often experience significant symptoms, require high intensive of end-of-life care
  - High degree of symptom-associated suffering
    - Pain: visceral pain, bone pain
    - Respiratory distress
    - GI symptom: vomiting, constipation, diarrhoea
    - CNS symptom: seizure, headache, paralysis
    - Fatigue
    - Drowsiness
    - Depressive symptom

End-of-life care and Bereavement

- Relative short time frame
- Intensive symptom control
- Parent grief: ***most severe, enduring and debilitating*** form of bereavement
    - *Queensland Health 2006*
- The events preceding child's death have significant influence on how the family grieve
- Multi-disciplinary support

Take Home Message

- *Early integration* of Palliative care in children with high risk malignancy is the standard of care
- *Good communication*:
  - Open communication, using understandable language, at the child's pace
- *Good symptom control*:
  - paediatric oncology patients have significant symptoms, intensive end-of-life care
- *Multidisciplinary bereavement support*


If there ever comes a day when we can't be together, keep me in your heart, I'll stay there forever.
- Winnie the Pooh

THANK YOU!