



Certificate Course in Paediatric Palliative Care Nursing 2019

Palliative Care in Neonatal Intensive Care Unit

YLCHAN/APN/NICU/UCH

Palliative care consists of three components

1. Pain and comfort management
2. Assist with end-of-life decision making
3. Bereavement support

(Romesberg, 2004)

The key roles of nurse in palliative care are to.....

- Establish a **good rapport** with the parents
- **Prepare the parents** to face their baby's impending death
- **Pay attention** to critically ill infant and their parents
- **Help parents to plan** what they want to do for their baby when he/she is still alive
- Let the parents **fulfill** their parent role and try to **create** memorable moments for the family.

Our Goals of Palliative Care are.....



The Framework of Palliative Care in NICU of UCH

Phase I

Anticipatory Grief Management

Phase II

Last Journey of the Dying Baby
with his/her Parents

Phase III

Follow up the Clustered Family &
Funeral Issues

Phase IV

Refer Bereavement Counseling
Service when in need

A Story of Baby Lucy (1)

- Baby Lucy and her sister were in vitro fertilization (IVF) twins
- They were born at 24 weeks of gestational age with birth weight 600gm and 613gm
- Before delivery, Baby Lucy's parents were interviewed by NICU team for ante-natal counselling

A Story of Baby Lucy (2)

- After stabilization of twins in NICU, parents came to visit their tiny babies
- Interviewed by primary doctor and nurse

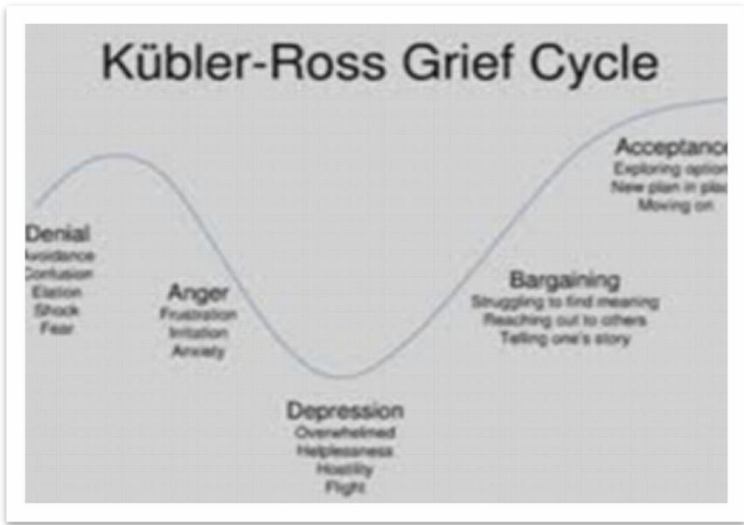
A Story of Baby Lucy (3)

- Baby Lucy with ventilator support after delivery and developed pulmonary haemorrhage on Day 3 of life
- Found to have progressive cerebellar haemorrhage on Day 4 due to failure control of bleeding
- Palliative care was initiated and interviewed with parents to discuss the plan of care

Phase I

Anticipatory Grief Management

Interview



End-of-life care plan for Baby Lucy

- Provide comfort care: continue to receive pain-relieve medication intravenously
- Play the parent role
- Baby Lucy pass away in “beautiful look” in parents’ arms
- Family members can visit
- Pray with chaplain
- Continue to day-to-day assessment, review care plan of Baby Lucy and parents

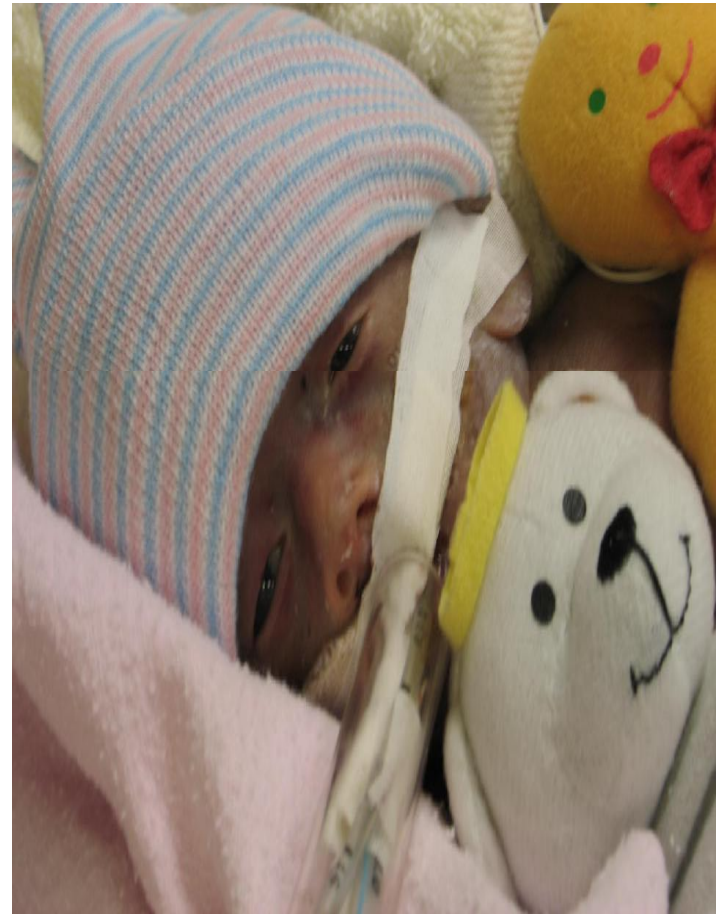
Decorate Baby Lucy's bedside



Create precious moment.....



Initiate concrete memory.....



Phase II

Last Journey of the Dying Baby Lucy with
her Parents

A Story of Baby Lucy (3)

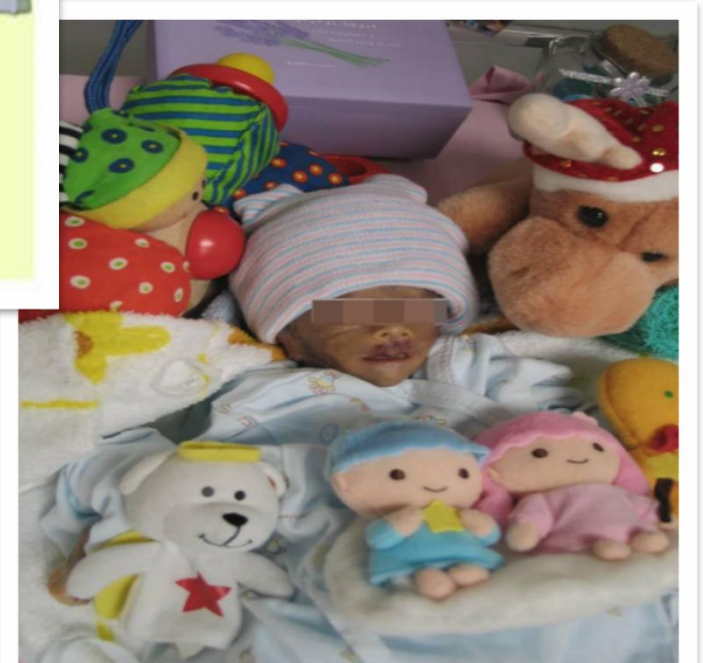
- She became deteriorating and poor control of critical condition with multi-organs failure.
- She was held in the arms of her loving parents and died peacefully on Day 7 of Life



Last office with parents



**Mother tailor-made
for her loved one**



Let the parents and family say “Good-bye” to Baby Lucy



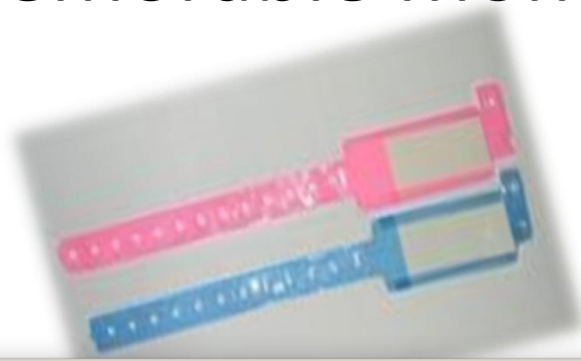
Provide privacy
–preferable a quiet room
with comfortable seats,
warm water, and tissue



After saying “Good bye”, Baby Lucy



Collect memorable moments.....



Phase III
Follow up the Clustered Family & Funeral
Issues

The choices of funeral arrangement



Parents chose hospital chapel for farewell Baby Lucy



Phase IV
Refer Bereavement Counseling Service
when in need

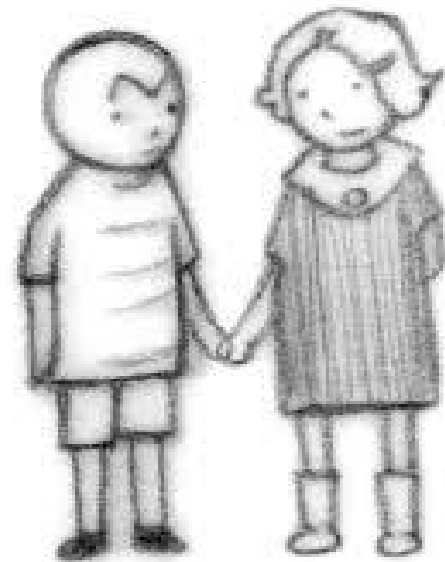


兒童癌病基金
Children's Cancer Foundation

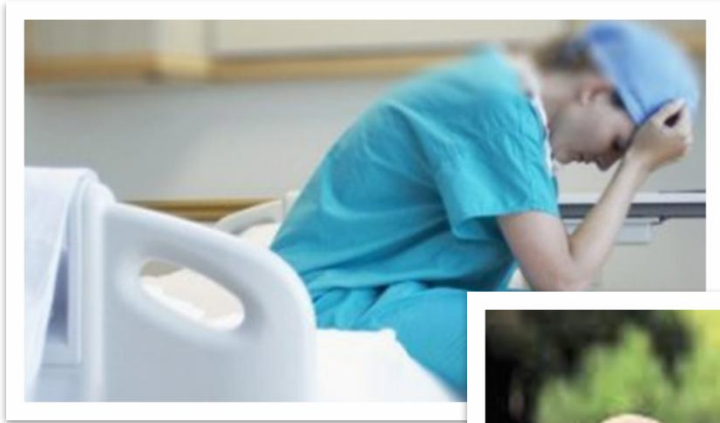


善寧會

Society for the Promotion of Hospice Care



Care of the carers



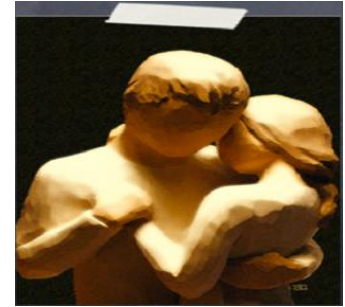
American Academy of Paediatrics Section on Hospice and Palliative Medicine and Committee on Hospital Care (2013) and Zhang & Lane (2013)

We integrate.....

“Palliative care ≠ being abandoned”

“Incurable disease ≠ nothing more we can offer”

A Story of Baby Lucy (4)



- Unfortunately, twin sister was found a brain tumor and required chemotherapy
- Baby Lucy's twin sister was discharged after 5 months of hospitalization
- Parents supported each other and they were facing this challenge positively

Look on the bright side.....



Take Home Message



**“Neither leading,
nor following,
but siding”**

- ***LISTEN*** the parents ***ACTIVELY***
- Identify the ***NEED*** and ***PLAN*** of period of pre-death, impending death and after death of infant
- Let the parents to have ***CHOICES***
- Provide ***QUALITY*** experiences to parents
- Leave the family with something ***POSITIVE*** to hold on to
- Care of the ***CARERS***

References

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Thank
you



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