

**Children's Palliative Care Foundation  
Inauguration  
cum  
Children's Palliative Care Symposium 2018**

**Bereavement Support in Neonatal  
Intensive Care**

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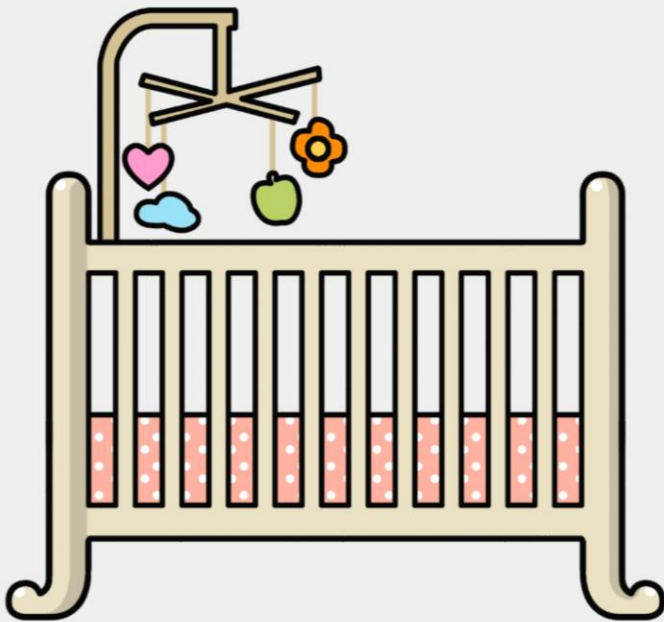
Neonatal Intensive Care Unit (NICU) is a  
place to.....



# Change of parents' expectation.....



# Parents in a foreign world.....



# 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 bereavement support 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.

# The data of deceased in NICU of UCH

	2013	2014	2015	2016	2017
Numbers of NICU admission	251	249	247	264	246
Numbers of deceased	7 (2.8%)	1 (0.4%)	5 (2.0%)	8 (3.0%)	6 (2.4%)
Maturity	Full term: 4 Preterm: 3	Full term: 1 Preterm: 0	Full term: 1 Preterm: 4	Full term: 2 Preterm: 6	Full term: 1 Preterm: 5
Diagnosis	<ul style="list-style-type: none"> <li>• Hypoplastic lung disease (1)</li> <li>• E. Coli septicaemia with severe brain damage (2)</li> <li>• Hypoxic-ischemic encephalopathy (HIE) (1)</li> <li>• Severe intraventricular haemorrhage (IVH) (2)</li> <li>• Multiple Congenital abnormalities (1)</li> </ul>	<ul style="list-style-type: none"> <li>• HIE and Cytomegalovirus infection (1)</li> </ul>	<ul style="list-style-type: none"> <li>• Hydrops fetalis (1)</li> <li>• Congenital Group B streptococcus (GBS) infection (1)</li> <li>• Necrotizing Enterocolitis (NEC) (1)</li> <li>• Hypoplastic lungs disease (1)</li> <li>• Severe IVH with pulmonary haemorrhage (1)</li> </ul>	<ul style="list-style-type: none"> <li>• Persistent Pulmonary Hypertension of Newborn (2)</li> <li>• GBS infection (2)</li> <li>• NEC of (2)</li> <li>• Multiple Congenital abnormalities (2)</li> </ul>	<ul style="list-style-type: none"> <li>• Hypoplastic heart disease (1)</li> <li>• GBS infection (2)</li> <li>• NEC (2)</li> <li>• E. Coli septicaemia with severe brain damage (1)</li> </ul>
Length of Stay	1 day to 3 months	30 days	1 day to 4 months	2 to 37 days	1 days to 4 months

# Bereavement Support Services in Paediatrics and Adolescent Department of United Christian Hospital

- Established in 1997
- A model of primary doctor and primary nurse to provide holistic family-centered care
- Inter-disciplinary team approach in daily operations



# Our Goals of Bereavement Support are.....



# The Framework of Bereavement Support 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)

- In vitro fertilization (IVF) twins
- Baby Lucy and her sister were born at 24 weeks of gestational age with birth weight 600gm
- Her twin's sister was 613gm
- After stabilization of twins, parents came to visit their tiny babies
- Interviewed by primary doctor and primary nurse

## A Story of Baby Lucy (2)

- 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

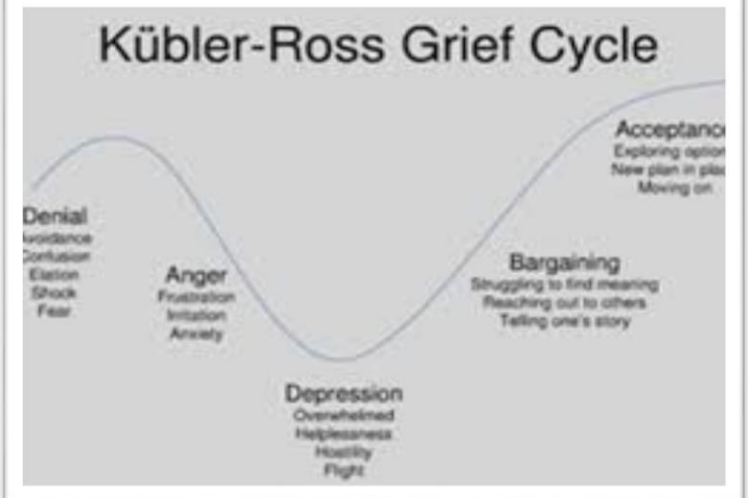
# Phase I

## Anticipatory Grief Management

# Interview



Master  
Listening Effective Body  
Language Well  
Business Cross Good Message Active  
Non-verbal  
Communication  
Empathic  
Cultural Listen  
Skills



# Subsequent Interview with parents

- Continued to provide dignity and respect to parents and Baby Lucy
- Provided comfort care in life-limiting situation

# End-of-life care plan for Baby Lucy

- 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 of Baby Lucy and parents



# Decorate Baby Lucy's bedside .....

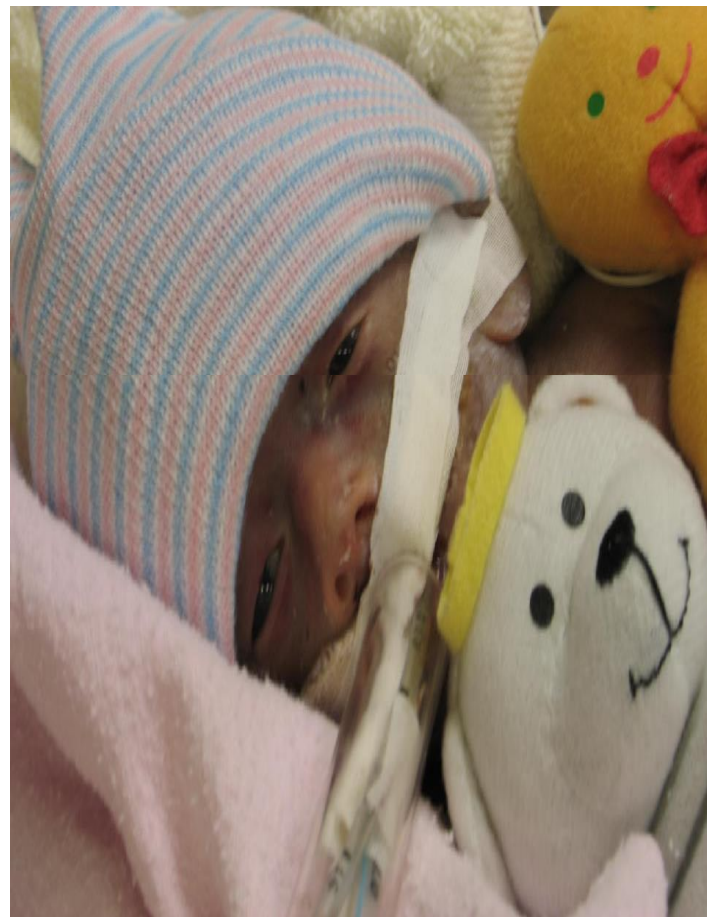


# Create precious moment.....





# 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 ....



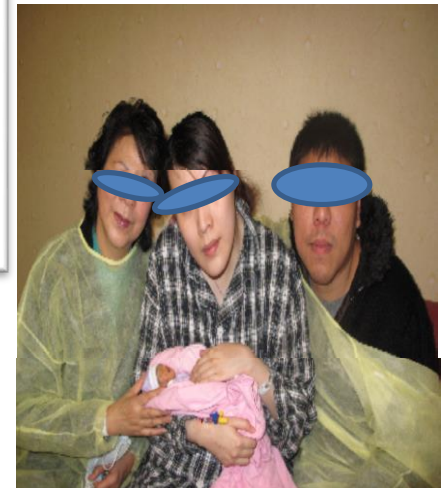
**Mother tailor-made  
for her loved one**



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

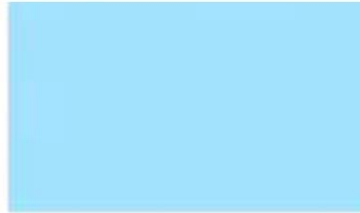


**Provide privacy –  
preferable a quiet room  
with comfortable seats,  
warm water, and tissue**



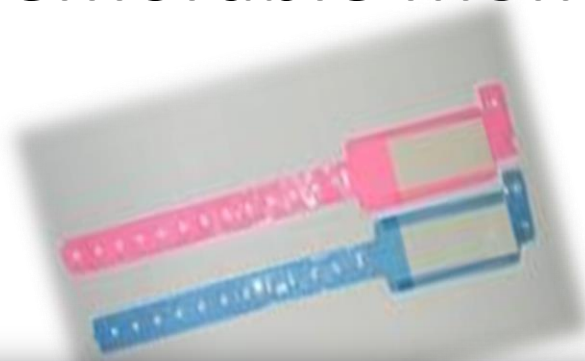


After saying “Good bye”, Baby Lucy .....





# 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

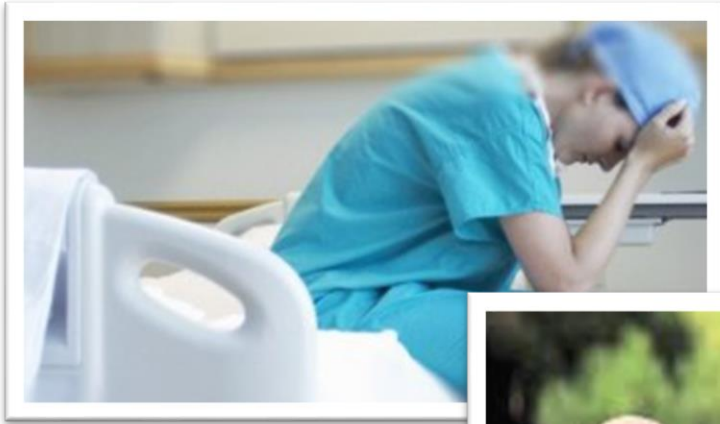




兒童癌病基金  
Children's Cancer Foundation



# 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.....



# Summary



"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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