CONFERENCE PROGRAMME BOOK

21st – 23rd August 2025

Putrajaya International Convention Centre (PICC)

Kuala Lumpur

Co-organised by: MAPAC MALAYSIAN ASSOCIATION OF PAEDIATRIC PALLIATIVE CARE

For More Enquiries:
☎ +6016 223 1357
✉ nccpcmmalaysia@gmail.com

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Welcoming Message

The overwhelming success of the 1st National Children Conference Palliative Care Malaysia (NCCPCM) 2022 has been an invigorating encouragement for the MAPPAC Committee to plan the **2nd NCCPCM on 21st-23rd August 2025 at the Putrajaya International Convention Centre, Kuala Lumpur, Malaysia**.

The theme for the conference will be, **"When Death is Inevitable, Life is a Choice."** Our focus will visibly encompass: End of life care for the children, Bereavement support and Talking about death to the children. 7 Plenary sessions and 13 Symposiums have been designed to support the conference theme. Key speakers from the United Kingdom, Korea, Singapore and Malaysian speakers will endeavour to deliver for your maximum learning needs.

Running parallel at the conference will be the **"Celebration of Life Festival."** It aims to:

- Raise awareness of the impermanence of life to inspire meaningful living.
- Promote cross-cultural understanding on traditions and perspectives regarding death.
- Foster open discussions about grief and loss, in helping to support mental health.
- Celebrate life even in the face of mortality through workshops, exhibitions, art, and other engaging activities.

The registration fees have been deliberately kept at an affordable level to enable many to participate. We welcome you to the conference with the opportunity to enjoy the fine framework on experimental learning and sharing.

Dr Lee Chee Chan
President MAPPAC and Organising
Chairman NCCPCM 2025

Organising Committees

Chairperson	Secretary	Treasurer
Dr. Lee Chee Chan	Mr. Michael Tan Teow Chye	Dr. Choong Yee Wan

Committee Members

Mr. Alvin Chong Chee Wei
Dr. Avinder Kaur A/P Sohan Singh
Mr. Alfred Gan Wei Yuan
Mr. Bary Joerius
Mr. Chew Weng Hong
Ms Elaine Teo Chiew Yian
Dr. Fahisham Taib
Ms. Fitri Damayanti Binti Hafizarli
Ms. Frieda Corrine Yang
Dr. Jee Rou Chen
Ms. Karen Kok Sher Yi
Ms. Lim Ee Sim
Ms. Liow Xin Yi
Ms. Nur Umairah Balqis Liong Binti Abdullah
Ms. Siti Murni Binti Mokhtar
Mr. Muhammad Arif Bin Aminuddin
Mr. Mohamad Fakrullah Bin Mohd Azlin
Dr. Nickson Tai Boon Khean
Dr. Ng Su Fang
Ms. Pearl Thor Mei Choo
Ms. Sally Lew Hsiao Yen
Dr. Sin Li Jie
Ms. Sharifah Husna Rahmah Binti S Badrul Hisham
Dr. Syarifah Najwa Binti Syed Mohamad
Ms. Sri Ram Seetha Arumugamm
Dr. Shamini Subramaniam
Mr. Tim Callaham
Dr. Teoh Yen Lin
Dr. Tay Chai Li
Dr. Tai Yi-Pinn
Ms. Tuan Yu Ming
Ms. Yap Suet Yen
Ms. Yee Chui Yoke
Mr. Yeoh Seng Huat

Congress Information

Official Venue

PUTRAJAYA INTERNATIONAL CONVENTION CENTRE (PICC)

Address: Jalan P5, Presint 5, 62000 Putrajaya, Malaysia

Google Map: https://g.co/kgs/YDftGBu Website: https://picc.gov.my

Parking

- There are 1,185 parking bays on four levels.
- Parking is free of charge.
- For the most convenient access to the event halls, we recommend the Green Zone (Zone B).

Registration Information

All participants are required to register at the Registration Counter daily. All congress delegates and exhibitors must wear their name tags at all times during the congress.

- Location : Concourse Level, Green Zone, Foyer Area of Hall B1 and B2
- Date and Time : 21st – 23th August 2025 starting from 730am

Registration Package included:

- Lanyard with name card
- Backpack with exclusive gifts from various sponsors
- Gala dinner ticket (for eligible participants only)

E-Certificate Of Attendance

- E-Certificate of Attendance will be emailed individually to participants within one month after the conference.
- To receive your certificate, participants must complete the daily feedback form by scanning the QR code displayed on the screens in both Hall B1 and Hall B2 for easy access.

Important Numbers

Emergency Hotline (Ambulance / Police / Fire)	**999**
Putrajaya Police Headquarters	**+60 3-8886 2222**
Putrajaya Fire & Rescue Department (Bomba)	**+60 3-8888 1222**
Hospital Putrajaya (24 hours)	**+60 3-8312 4200**

2nd NCCPCM Programme Schedule

21st August 2025 (Thursday, Day 1)

<table>
<tr><th>Time</th><th>Venue</th><th colspan="2">Programme</th><th>Speaker</th></tr>
<tr><td>0730-0815</td><td colspan="4">Registration</td></tr>
<tr><td>0815-0930</td><td><i>Hall B2</i></td><td colspan="3">Opening Ceremony</td></tr>
<tr><td>0930-1015</td><td><i>Hall B2</i></td><td colspan="2">Plenary 2: End of Life Care in Paediatric Setting: UK Experiences</td><td>Speaker: Professor Dr. Richard D. W. Hain
Chairperson: Dr. Shamini Subramaniam</td></tr>
<tr><td>1015-1030</td><td colspan="4">Tea Break</td></tr>
<tr><td>1030-1115</td><td><i>Hall B2</i></td><td colspan="2">Plenary 1: Paediatric Palliative Care in Malaysia – Where Are We (Past, Current, Future)?</td><td>Speaker: Dr. Lee Chee Chan
Chairperson: Dr. Shamini Subramaniam</td></tr>
<tr><td>1115-1200</td><td><i>Hall B2</i></td><td colspan="2">Plenary 3: Cultural Perspectives on Death: Navigating Beliefs and Perspectives</td><td>Speaker: Dr. Anna-Karenia (AK) Anderson
Chairperson: Dr. Sharifah Najwa Bt Syed Mohamad</td></tr>
<tr><td></td><td colspan="2"><i>Venue: Hall B2</i></td><td colspan="2"><i>Venue: Hall B1</i></td></tr>
<tr><td>1200-1315</td><td colspan="2">Symposium 1:
Skin Care at the End of Life
Chairperson: Dr. Tai Yi-Pinn

Speaker: Dr. Leong Kin Fon
Topic : Life-limiting Skin Disorders in Children- Issues and Challenges

Speaker: Ms. Elaine Teo Chiew Yian
Topic : Touching the Untouchable: Skin, Dignity, and the Unseen Comforts of Community Paediatric Palliative Care</td><td colspan="2">Symposium 2:
Grief and Bereavement Process
Chairperson: Ms. Fitri Damayanti Binti Hafizarli

Speaker: Dr. Lynda Ling Sai Ang
Topic : How Can You Support A Family's Grieving Process After the Death of A Child?

Speaker: Ms. Sri Ram Seetha Arumugamm
Topic : The Role of Play Therapy in Grief and Bereavement Support</td></tr>
<tr><td>1315-1415</td><td colspan="4">Lunch</td></tr>
</table>

	Venue: Hall B2	***Venue: Hall B1***
1415-1530	**Symposium 3:** **Symptom Management at End of Life** **Chairperson:** Dr. Sin Li Jie **Speaker:** Professor Dr. Richard D.W.Hain **Topic** : Identification and Management of Terminal Pain and Restlessness **Speaker:** Dr. Nickson Tai Boon Khean **Topic** : Challenges and Strategies of Managing Pain at Home	**Symposium 4:** **Ceremonies and Rituals at End of Life** **Chairperson:** Ms. Yee Yit Cheng **Speaker:** Venerable Tian Wen **Topic** : Spiritual Care for Children and Family at End Of Life **Speaker:** Dr. Fahisham Taib **Topic** : The Different Rituals and Practices in Malaysia
1530-1545	**Tea Break**	
1545-1700	**Symposium 5:** **Advance Care Plan (ACP)** **Chairperson:** Dr. Teoh Yen Lin **Speaker:** Dr. Lee Chee Chan **Topic** : How to Initiate ACP Discussion? **Speaker:** Dr. Anna-Karenia (AK) Anderson **Topic** : How to Implement the Content of ACP into the Health System?	**Symposium 6:** **Multidisciplinary Care for End of Life** **Chairperson:** Ms. Liow Xin Yi **Speaker:** Ms. Maggie@Nur Umairah Liong **Topic** : How Can A Nurse Support ACP Implementation? **Speaker:** Ms. Nur Sakinah Ibrahim **Topic** : Nutritional Management at End of Life
End of Day 1		

<table>
<tr><th colspan="5">22nd August 2025 (Friday, Day 2)</th></tr>
<tr><th>Time</th><th>Venue</th><th colspan="2">Programme</th><th>Speaker</th></tr>
<tr><td rowspan="3">0730-0815</td><td colspan="4">Registration</td></tr>
<tr><td colspan="2"><i>Venue: Hall B2</i></td><td colspan="2"><i>Venue: Hall B1</i></td></tr>
<tr><td colspan="2">Meet The Expert 1
Professor Dr. Richard D. W. Hain</td><td colspan="2">Meet The Expert 2
Dr. Michelle Koh Li-Hua</td></tr>
<tr><td>0830-0915</td><td><i>Hall B2</i></td><td colspan="2">Plenary 4: Advance Care Plan: Burden or A Tool for End-of-Life Care?</td><td>Speaker: Dr. Michelle Koh Li-Hua
Chairperson: Dr. Sin Li Jie</td></tr>
<tr><td>0915-1000</td><td><i>Hall B2</i></td><td colspan="2">Plenary 5: Discussing Death and Dying with Children: Should We?</td><td>Speaker: Dr Kim Min Sun
Chairperson: Dr. Sin Li Jie</td></tr>
<tr><td>1000-1015</td><td colspan="4">Tea Break</td></tr>
<tr><td></td><td colspan="2"><i>Venue: Hall B2</i></td><td colspan="2"><i>Venue: Hall B1</i></td></tr>
<tr><td>1015-1130</td><td colspan="2">Symposium 7:
Medications at End of Life
Chairperson: Ms. Yap Suet Yen

Speaker: Ms. Emeline Lew Siok Yin
Topic : Challenges of Polypharmacy

Speaker: Ms. Nurhidayah binti Rosli
Topic : Opioid Counselling</td><td colspan="2">Symposium 8:
Communication with Children
Chairperson: Ms. Sri Ram Seetha Arumugamm

Speaker: Dr. Lynda Ling Sai Ang
Topic : Facilitate Communication for Death and Dying with Family & Community

Speaker: Dr. Shamini Subramaniam
Topic : Strategies to Initiate the Discussions on Death and Dying to Paediatric Patients</td></tr>
<tr><td>1130-1245</td><td colspan="2">Symposium 9:
Technology and Innovation for End of Life Care
Chairperson: Ms. Tuan Yu Ming

Speaker: Dr. Jee Rou Chen
Topic : The Role of Rehabilitation for Children with Palliative Care Needs

Speaker: Ms. Siti Anis binti Ab. Rahim
Topic : The Role of Occupational Therapy for Children with Palliative Care Needs</td><td colspan="2">Oral Presentation
Chairperson: Dr. Ng Su Fang

Judges:
• Associate Professor Dr. Tan Chai Eng
• Dr Intan Nor Chahaya Bt Shukor

Poster Presentation:
Chairperson: Dr. Teoh Yen Lin

Judges:
• Associate Professor Datuk Dr. Kuan Geok Lan
• Dr. Aaron Hiew Wi Han</td></tr>
<tr><td>1245-1400</td><td colspan="4">Lunch</td></tr>
</table>

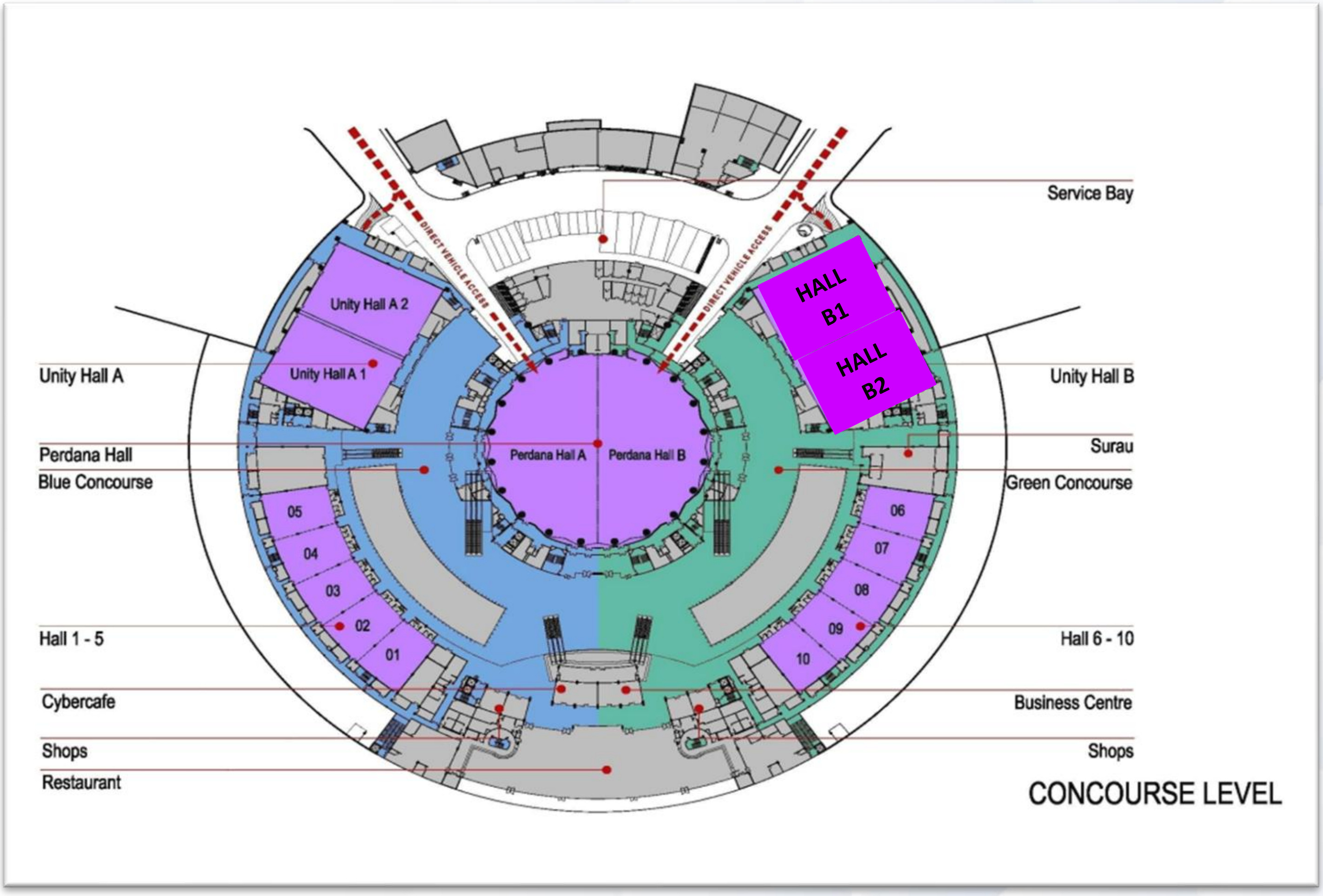
	Venue: Hall B2	***Venue: Hall B1***
1400-1515	**Symposium 11:** **Future Direction and Research** **Chairperson:** Ms. Maggie@ Nur Umairah Liong **Speaker:** Dr. Fahisham Taib **Topic** : Expansion of Concept and Service of Paediatric Palliative Care in the Future **Speaker:** Dr. Chua Ker Yang **Topic** : Research Needs for A Good Death	**Symposium 10:** **Complementary Therapy in Paediatric Palliative Care** **Chairperson:** Ms. Emeline Lew Siok Yin **Speaker:** Dr. Ho Sin Khee **Topic** : The Role of Traditional Chinese Medicine **Speaker:** Ms. Feli Hoo Fui Mooi **Topic** : The Role of Aromatherapy
1515-1530	**Tea Break**	
1530-1645	**Symposium 13:** **Legality and Policy** **Chairperson:** Ms. Elaine Teo Chiew Yian **Speaker:** Dr. Kim Min Sun **Topic** : Challenges of A Good Death in Korea **Speaker:** Dr. Michelle Koh Li-Hua **Topic** : Limitations and Challenges for Paediatric Palliative Care Service in Singapore	**Symposium 12:** **Resilience of Caregivers** **Chairperson:** Dr. Ng Su Fang **Speaker:** Ms. Tan Hui Sin **Topic** : It Takes A Village: Social Support for Caregivers in Paediatric Palliative Care **Speaker:** Dr. Tay Chai Li **Topic** : The Role of Children's Hospice in Malaysia
1900-2200	***Hall 9-10***	**Gala Dinner**
End of Day 2		

23rd August 2025 (Saturday, Day 3)

Time	Venue	Programme	Speaker
0730-0815	**Registration**		
	Venue: Hall B2		***Venue: Hall B1***
	Meet The Expert 3 Dr. Anna-Karenia (AK) Anderson		**Meet The Expert 4** Dr. Kim Min Sun
0830-0915	***Hall B2***	**Plenary 6:** Paediatric Breakthrough Pain: Challenges and Recent Development	**Speaker:** Professor Dr. Richard D. W. Hain **Chairperson:** Dr. Nickson Tai Boon Khean
0915-1000	***Hall B2***	**Plenary 7:** Future Directions in Paediatric Palliative Care: Innovations and Challenges Ahead	**Speaker:** Dr. Anna-Karenia (AK) Anderson **Chairperson:** Dr. Nickson Tai Boon Khean
1000-1015	**Tea Break**		
1015-1100	***Hall B2***	**Plenary 8:** Research Advances in Paediatric Palliative Care: What's New?	**Speaker:** Dr. Michelle Koh Li-Hua **Chairperson:** Dr. Shamini Subramaniam
1100-1200	**Closing Ceremony**		
1200-1300	**Lunch**		

End of Day 3
Thank you!

Floor Plan



The conference will take place in **Hall B1** and **Hall B2** of the **Putrajaya International Convention Centre (PICC)**.

Registration Counter: Located at the Concourse Level, Green Zone,
Foyer Area of Hall B1 & B2.

Main Conference Sessions: Hall B1 & B2

Booth Exhibition: Hall 6

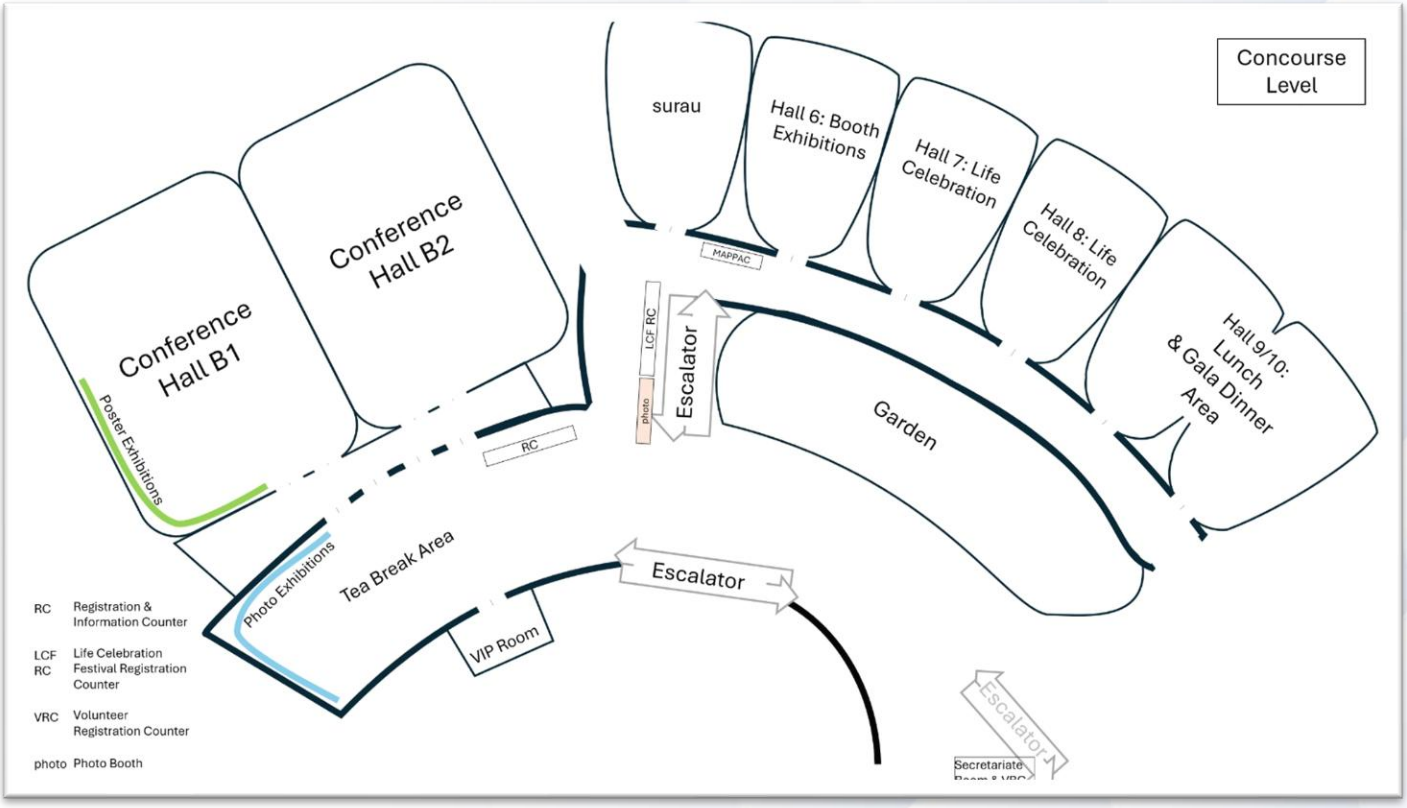
Poster Presentations: Hall B1 inside wall area

Life Celebration Festival: Hall 7 & 8

Gala Dinner and Lunch: Hall 9 & 10 (evening setup)

Restrooms: Located near the foyer, opposite the registration counter. Inclusive of OKU-accessible toilet

Floor Plan



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Gala Dinner and Lunch: Hall 9 & 10 (evening setup)

Restrooms: Located near the foyer, opposite the registration counter. Inclusive of OKU-accessible toilet

Conference Speakers

Professor Dr. Richard D. W. Hain

- Consultant & Clinical Lead in Paediatric Palliative Medicine, Wales
- Honorary Professor in Clinical Ethics, Swansea University
- Pioneer in Paediatric Palliative Medicine in the UK
- Editor and Author – Oxford Textbook of Palliative Care for Children
- Award-Winning Expert in Palliative Care & Ethics

Dr. Anna-Karenia (AK) Anderson

- Consultant in Paediatric Palliative Medicine, Royal Marsden Hospital, London and Shooting Star Children's Hospice, Guildford
- Chair, Association for Paediatric Palliative Medicine (APPM)
- Leader in Global Paediatric Palliative Care Development

Dr. Michelle Koh Li-Hua

- Consultant in Paediatric Palliative Medicine, KK Women's and Children's Hospital, Singapore
- Global Leader in Paediatric Palliative Care Development SINGAPORE

Dr. Kim Min Sun

- Clinical Associate Professor, Department of Pediatrics, Seoul National University Hospital
- Director, Nexon Integrated & Respite Care Center for Children
- Expert in Pediatric Palliative Care & Home Medical Care KOREA

Conference Speakers

Dr. Lee Chee Chan

- Consultant Paediatric Palliative Medicine Specialist, Hospital Tunku Azizah (HTA), Kuala Lumpur, Malaysia
- President of Malaysian Association of Paediatric Palliative Care (MAPPAC), Kuala Lumpur, Malaysia

* * *

Dr. Fahisham Taib

- Paediatric Palliative Medicine Specialist, Hospital Pakar Universiti Sains Malaysia, Kelantan, Malaysia
- Committee of Malaysian Association of Paediatric Palliative Care (MAPPAC), Kuala Lumpur, Malaysia

* * *

Dr. Leong Kin Fon

- Consultant Paediatric Dermatologist, Hospital Tunku Azizah (HTA), Kuala Lumpur, Malaysia

* * *

Dr. Lynda Ling Sai Ang

- Principal Counsellor, Hills and Valleys Therapy and Learning Centre, Kuala Lumpur, Malaysia

Conference Speakers

Dr. Jee Rou Chen

- Rehabilitation Specialist, Sarawak General Hospital, Sarawak, Malaysia
- President, MAPPAC Malaysian Children's Hospice (Sibu), Sarawak, Malaysia

Dr. (PhD) Ho Sin Khee

- Traditional Chinese Medicine (TCM) Practitioner, Mentors Traditional Chinese Medicine (TCM) Healthcare Center, Malaysia.

Venerable Tian Wen

- Healthcare Chaplain, Universal Kindness Caring Buddhist Society, Kuala Lumpur, Malaysia

Ms. Feli Hoo Fui Mooi

- Ayurvedic Practitioner, Clinical Aromatherapist, Expressive Art Therapist, Ayurvedic and Aromatherapy Holistic Health Care Center, Selangor, Malaysia.

Dr. Nickson Tai Boon Khean

- Paediatric Palliative Medicine Specialist, Sarawak General Hospital, Sarawak, Malaysia

Dr. Shamini Subramaniam

- Paediatric Palliative Medicine Specialist, Hospital Tunku Azizah (HTA), Kuala Lumpur, Malaysia

Dr. Chua Ker Yang

- Paediatrician, Hospital Tunku Azizah (HTA), Kuala Lumpur, Malaysia

Ms. Maggie@Nur Umairah Liong

- Paediatric Palliative Care Nurse, Hospital Tunku Azizah (HTA), Kuala Lumpur,

Conference Speakers

Ms Elaine Teo Chiew Yian

- Children's Hospice Nurse, MAPPAC Malaysian Children's Hospice (Kuala Lumpur), Kuala Lumpur, Malaysia

Ms Nurhidayah binti Rosli

- Pharmacist, Hospital Tengku Permaisuri Norashikin Kajang (HTPN), Selangor, Malaysia

Ms Sri Ram Seetha Arumugamm

- Child Play Therapist, MAPPAC Malaysian Children's Hospice (Kuala Lumpur), Kuala Lumpur, Malaysia

Ms Nur Sakinah Ibrahim

- Clinical Dietitian, Dietetic & Foodservice, Hospital Tunku Azizah (HTA), Kuala Lumpur, Malaysia

Ms Tan Hui Sin

- Medical Social Worker, Hospital Queen Elizabeth, Sabah, Malaysia

Ms Emeline Lew Siok Yin

- Pharmacist, Hospital Tunku Azizah (HTA), Kuala Lumpur, Malaysia

Dr. Tay Chai Li

- Children's Hospice Doctor, MAPPAC Malaysian Children's Hospice (Klang), Selangor, Malaysia

Ms Siti Anis binti Ab. Rahim

- Paediatric Occupational Therapist, University of Malaya, Kuala Lumpur, Malaysia

2nd National Conference of Children's Palliative Care Malaysia (NCCPCM) 2025

Co-organised by:

For More Enquiries:
☎ +6016 223 1357
✉ nccpcmmalaysia@gmail.com

Opening Ceremony

When Death is Inevitable, Life is a Choice

~ PROGRAMME ~

8.15AM : Announcement of VIP Arrival

8.20AM : National Anthem & Opening Prayer

8.30AM : Opening Performance

8.40AM : Opening Video

8.45AM : Welcome & Opening Speech

9:05AM : Official Launch of the 2nd NCCPCM, Life Celebration Festival & Handbook of Children Palliative Care Malaysia (2nd Edition)

9.15AM : Tour of Conference Exhibition & Life Celebration Festival for VIP, & Refreshments for VIP

21 AUGUST 2025, 8.15 – 9.30AM

PUTRAJAYA INTERNATIONAL CONVENTION CENTRE

THANK YOU TO ALL OUR SPONSORS!

2nd National Conference of Children's Palliative Care Malaysia (NCCPCM) 2025

Gala Dinner

Come Celebrate with Us

~ PROGRAMME ~

6.30 PM : Registration & Welcome Reception

7.00 PM: Opening Speech & Acknowledgement

7.30 PM: Start of Dinner Service & Performances

8.30 PM: Awards & Recognition

9.00 PM: Games

9.30 PM: Lucky Draw

10.00 PM: End of the Night

22 AUGUST 2025, 7.00 - 10.00PM

PUTRAJAYA INTERNATIONAL CONVENTION CENTRE

THANK YOU TO ALL OUR SPONSORS!

Abstract Content

Oral Presentation

Abstract No.	Title	Corresponding Author
OP1	**Perceptions of Adult Palliative Care Physicians on the Transition of Pediatric Palliative Care Patients to Adult Services**	Fahisham Taib
OP2	**Childhood Mortality with Life Limiting Illness Based on Malaysia National Mortality Data 2014-2022**	Chua Ker Yang
OP3	**Empowering Parents: A Caregiver Workshop for Families of Children with Severe Neurological Impairment**	Charlotte Gan Ying Shi
OP4	**Evaluating the Efficacy and Sustainability of the New Bereavement Care Plan in The Paediatric Department, Hospital Seberang Jaya Over a 14 Month Period**	Darwitha Sivanendran
OP5	**Development and Pilot Testing of a Questionnaire Assessing Caregiver's Knowledge, Attitude and Practice (KAP) on Opioid Use in Pediatric Palliative Care (PPC) at a Tertiary Hospital in Malaysia**	Nurhidayah Rosli
OP6	**A Comparative Study on the Knowledge of Medical Officers Regarding Advance Care Plan (ACP) Discussions in Hospitals With and Without Paediatric Palliative Care Services**	Yan Wen Ng

Poster Presentation

Abstract No.	Title	Corresponding Author
PP1	**A Descriptive Review on Children Receiving Specialised Paediatric Palliative Care at Hospital Shah Alam**	Winnie Ng Hui Ching
PP2	**A Descriptive study on Perinatal Palliative Care Services at Hospital Tunku Azizah, Kuala Lumpur**	Shamini Subramaniam
PP3	**The Use of the Pediatric Palliative Screening Scale (PaPaS) Score as A Routine Screening Instrument in Pediatric Oncology Patients: A Single-center Descriptive Cross-Sectional Study**	Reganedgary Jonlean
PP4	**Ethics in Paediatric Palliative Care: A Case Study from a District Hospital in Sarawak**	Nicole Phing Jie Hoo
PP5	**The Burden of Palliative Care for Children with Congenital Heart Disease: a Cardiac Center Experience in Malaysia**	Betsy Christina Steven
PP6	**Buttons That Speak: Connecting with Adolescents and Young Adults in Palliative Care**	Shamini Subramaniam
PP7	**Dietitian-Led Nutritional and Palliative Care in an Infant with DiGeorge Syndrome and Congenital Heart Disease: A Case Report**	Hamidah Osman

PP8	**Common Medications Used by Neuropalliative Clinic in Hospital Tunku Azizah, Kuala Lumpur**	Emeline Siok Yin Lew
PP9	**Multidisciplinary Nutritional Rehabilitation and Challenges in Nutritional Management of Syndromic Infants with Severe Malnutrition: A Case Series Involving Integration of Dual-Centre Care**	Hamidah Osman
PP10	**Advanced Care Planning in Paediatric Palliative Care Patients at Hospital Tunku Azizah**	Sin Li Jie
PP11	**Preferred Place of Death: Part of Advance Care Planning for Paediatric Palliative Care Patients**	Alia Abdul Aziz Cooper
PP12	**Patient-controlled Analgesia by Paediatric Palliative Care Unit in Hospital Tunku Azizah**	Bary Joeriuse
PP13	**Occupational Therapy Recommendations for Aids, Adaptation and Assistive Equipment for Paediatric Palliative Patients at Hospital Tunku Azizah Kuala Lumpur**	Wennie Patin
PP14	**The Last Act of Love: A Young Lady's Decision to Hold Her Own Living Funeral**	Xanicia Long
PP15	**Memory Making Using Footprints for Paediatric Palliative Patients in Hospital Tunku Azizah**	Sharifah Husna Rahmah S Badrul Hisham
PP16	**Understanding the Profile and Motivation of Volunteers in Children's Palliative Care: A Descriptive Study in MAPPAC**	Tay Chai Li

PP17	**The Last Chapter: Expectations and Insights on End-of-Life Care from Healthcare Professionals**	Fahisham Taib
PP18	**"In Their Shoes": Understanding Caregiving Needs from Parents of Children Receiving Palliative Care in Our Community**	Elaine Teo Chiew Yian
PP19	**Telling the Truth: A Powerful Perspective of a Child on Disclosure of Medical Information**	Agnes Suganthi Thinakaran
PP20	**The Shape of Goodbye: Exploring Grief and Meaning-Making Through Clay in Clinical Review**	Sri Ram Seetha Arumugamm
PP21	**Paving the Way for Dignity in Health Care for Children with Serious Illnesses in the West of Nepal**	Amrita Shrestha

***** Full Abstract at APPENDIX 1- Abstract Book***

Life Celebration Festival Programme Schedule

Day 1 – 21st August 2025, Thursday

Time	Programme	
	Venue: Hall 7	**Venue: Hall 8**
0900-1400	**Coffin Lying Experience with Guide from Volunteer**	**Book Reading Corner** **Memorial Wall**
1400-1500		**How to Write My Will Before I Die?** *(Language: English)* **Speaker:** Mr. Joseph Yu Shi Yang **Chairperson:** Ms. Elaine Teo Chiew Yian
1500-1630		**My Beloved Grandmother Picture Book Sharing: A Journey Exploring Life and Death with Children** *(Language: Chinese)* **Facilitator:** Ms. Aw Pei Xin
1630-1700		

Day 2 - 22 August 2025, Friday

Time	Programme	
	Venue: Hall 7	**Venue: Hall 8**
0900-1000	**Coffin Lying Experience with Guide from Volunteer**	**Book Reading Corner** **Memorial Wall**
1000-1200		**Death Café - Talk about death** *(Language: Chinese)* **Moderator:** Dr Lee Chee Chan
1200-1300		**Book Reading Club** *(Language: Chinese)* **Moderator:** Dr Lee Chee Chan
1300-1400		**Book Reading Corner** **Memorial Wall**
1400-1500	**A Journey Within: The Coffin Lying Experience by Xiao En** *(Language: English)* **Facilitator:** Mr. Quek Ser Pin & Ms. Louise Lai Fu Yee	
1500-1700		**How to Talk to Children about Death and Dying through Play?** *(Language: English)* **Speaker:** Ms. Sri Ram Seetha Arumugamm **Chairperson:** Ms. Sally Lew Hsiao Yen

Day 3 - 23 August 2025, Saturday

Time	Programme	
	Venue: Hall 7	**Venue: Hall 8**
0900-1000	**Coffin Lying Experience with Guide from Volunteer**	**Craft Session** *(Language: Chinese)* **Moderator:** Ms. Wong Hooi Pheng
1000-1130		**A Journey of Compassion and Self-discovery** *(Language: Chinese)* **Speakers:** Life Practitioners **Chairperson:** Ms. Tay Chai Li
		Venue: Hall B1
1130-1200		**The Best Farewell: Let Love Remain, Not Regret** *(Language: Chinese)* **Speakers:** Mr. Fong Yee Leong **Chairperson:** Mr. Alvin Chong Chee Wei
1200-1300		
The End **Thank You!**		

Life Celebration Festival Posters

LIFE CELEBRATION FESTIVAL 生命嘉年华

2nd National Conference of Children's Palliative Care Malaysia 2025
When Death is Inevitable, Life is a Choice

XIAO EN

PUBLIC TALK | 公开讲座

HOW TO WRITE MY WILL BEFORE I DIE? (English talk)

我去世前该如何立遗嘱？(英文讲座)

"Celebrating life" is not just a call to live with dignity, but also an exhortation to lovingly make provision for those we care about. It is painful to imagine our loved ones continuing on in this world without us; however, having clear plans in place can help us to resolutely accept the inevitability of death.

"庆祝生命"不仅是呼吁有尊严地生活，更是鼓励我们以爱为所关心的人做好安排。想象亲人没有我们继续生活在这个世界上是痛苦的；然而，提前做好清晰的规划，有助于我们坚定地接受死亡的必然性。

Speaker 分享人:

Joseph Yu
(Lawyer/律师)

21 August 2025, Thursday

2pm - 3pm

Hall 8, Concourse Level, PICC

For more information please visit: **www.mappac.org/nccpcm_malaysia**

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LIFE CELEBRATION FESTIVAL 生命嘉年华

2nd National Conference of Children's Palliative Care Malaysia 2025
When Death is Inevitable, Life is a Choice

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WORKSHOP | 工作坊

PICTURE BOOK SHARING: A JOURNEY EXPLORING LIFE AND DEATH WITH CHILDREN (Language: Chinese)

《亲爱的外婆》绘本分享：开启亲子间生命对话的起点(语言:中文)

Life doesn't follow a fixed formula and neither does My Beloved Grandmother. Instead of a traditional, instruction-heavy reading, the facilitator will gently guide participants through the book's illustrations, quiet spaces, and open-ended words, inviting both adults and children to reflect and begin heartfelt conversations about life.

生命从来没有一定的方程式，《亲爱的外婆》亦是如此。摆脱填鸭式的导读，分享者将透过绘本中的图像、留白空间与未说尽的文字，让大人与小孩从中开启对生命思考与对话的起点。

Facilitator 引导人:

Aw Pei Xin (K.B.; P.A.)
區佩欣
Registered Counsellor
注册与执证心理辅导师

21 August 2025, Thursday

3pm - 4:30pm

Hall 8, Concourse Level, PICC

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WORKSHOP | 工作坊

DEATH CAFÉ – TALK ABOUT DEATH

(Language: Chinese)

生死咖啡馆 - 谈论死亡 (语言:中文)

Participants are encouraged to share their experiences related to death and dying through a range of interactive activities, including Q&A sessions, art expression, and button games. These shared experiences foster mutual learning and reflection, enabling individuals to derive meaningful insights and develop positive values and future plans. **This session comes with an instant coffee drink.**

鼓励参与者通过一系列互动活动分享自己与死亡相关的经验，包括问答环节、艺术创作和纽扣游戏等。这些分享将促进彼此学习与反思，帮助个人获得有意义的领悟，并培养正向的价值观与未来规划。**本环节提供免费即溶咖啡饮用。**

Moderator 主持人:

Dr Lee Chee Chan
李知展医生
Consultant in Paediatric Palliative Medicine, HTA
吉隆坡中央医院
儿童安宁疗护专科医生

22 August 2025, Friday

10am - 12pm

Hall 8, Concourse Level, PICC

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WORKSHOP | 工作坊

BOOK READING CLUB (Language: Chinese)

【孩在继续】读书会 (语言:中文)

Participants are encouraged to read any stories from the book [孩在继续], followed by opportunities to share their perspectives, engage in thoughtful debates on key issues, reflect on their personal experiences, and ultimately develop new insights into paediatric palliative care.

鼓励参与者阅读《孩在继续》一书中的任意故事，并在之后分享自己的观点，围绕关键议题展开深入讨论，反思个人经历，并最终对儿童安宁疗护发展出新的见解。

Moderator 主持人:

Lee Jie
李颉
(Author/作者)

22 August 2025, Friday

12pm - 1pm

Hall 8, Concourse Level, PICC

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WORKSHOP | 工作坊

A JOURNEY WITHIN: THE COFFIN LYING EXPERIENCE BY XIAO EN

(Language: English)

练习告别：躺棺体验工作坊 (语言：英文)

Step into a coffin - and into yourself.
This powerful experience invites you to reflect on life through the lens of death and rediscover what truly matters.

躺棺体验并与自己相遇。透过一次深刻的告别体验，重新看见生命的价值与方向。

22 August 2025, Friday
2pm - 5pm
Hall 7, Concourse Level, PICC

Facilitator 引导人:
Quek Ser Pin (K.B.; P.A.)
郭思彬
Senior Registered Counsellor
注册与执证心理辅导师

Facilitator 引导人:
Louise Lai Fu Yee (K.B.; P.A.)
赖玞妤
Senior Registered Counsellor
注册与执证心理辅导师

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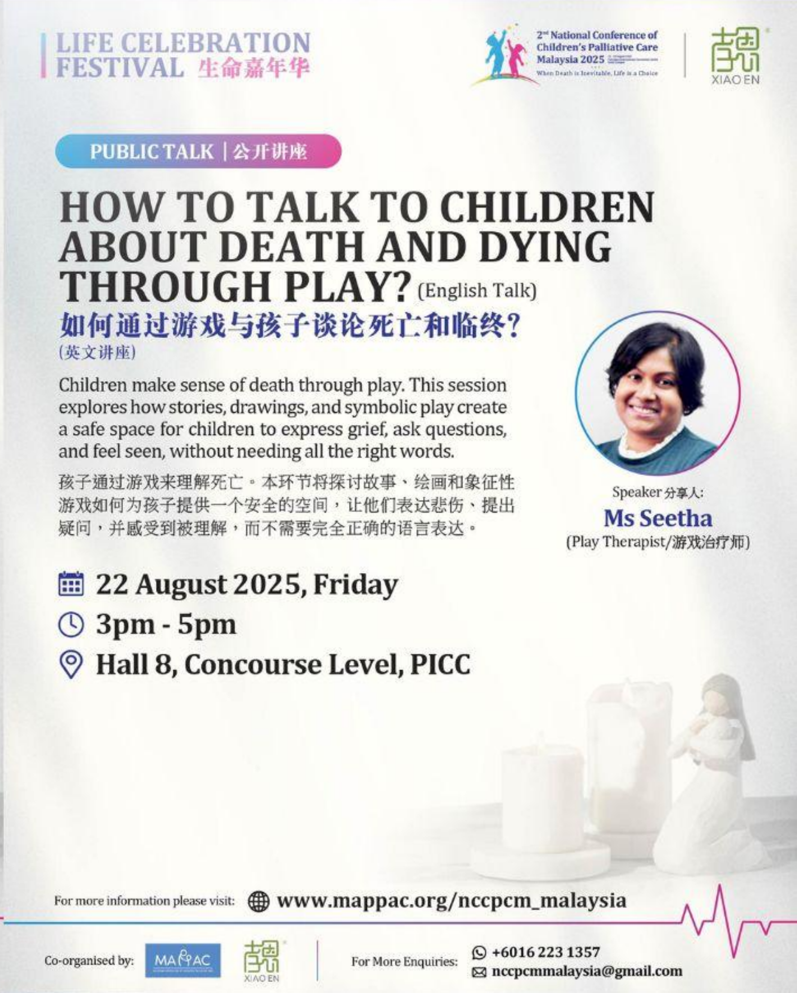

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XIAO EN

PUBLIC TALK | 公开讲座

HOW TO TALK TO CHILDREN ABOUT DEATH AND DYING THROUGH PLAY?

(English Talk)

如何通过游戏与孩子谈论死亡和临终？
(英文讲座)

Children make sense of death through play. This session explores how stories, drawings, and symbolic play create a safe space for children to express grief, ask questions, and feel seen, without needing all the right words.

孩子通过游戏来理解死亡。本环节将探讨故事、绘画和象征性游戏如何为孩子提供一个安全的空间，让他们表达悲伤、提出疑问，并感受到被理解，而不需要完全正确的语言表达。

Speaker 分享人:
Ms Seetha
(Play Therapist/游戏治疗师)

22 August 2025, Friday
3pm - 5pm
Hall 8, Concourse Level, PICC

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WORKSHOP | 工作坊

CRAFT SESSION

(Language: Chinese)

手工艺工作坊 (语言:中文)

Activity1: Glitter calm down Jar
Objective: To help individual to manage his or her strong emotion and promote relaxation through visual & sensory engagement.

Activity2: Origami heart
Objective: To boost us up moving on our life journey

活动1：闪粉冷静瓶
目标：通过视觉和感官的参与，帮助个人疏解强烈情绪，促进放松。

活动2：爱心折纸
目标：激励、鼓舞我们在人生路上继续往前走。

Moderator 主持人:
Wong Hooi Pheng
黄爱萍
Registered Counsellor (K.B.; P.A.),
Structural Play Therapist
马来西亚注册辅导师
结构式游戏治疗师

23 August 2025, Saturday
9am - 10am
Hall 8, Concourse Level, PICC

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PUBLIC TALK | 公开讲座

A JOURNEY OF COMPASSION AND SELF-DISCOVERY

(Chinese Talk)

渡人是一种能力，渡己是一场修行(中文讲座)

Peace in life and death is their daily devotion. They walk with the departed, witness regrets, and remind us to live fully. Listen to their stories, you might just find light for your own.

生死两相安，是他们每日的修行。他们是送别现场的第一线，见过无数遗憾，也提醒我们，珍惜当下，别等来不及。听见他们的故事，或许，也能照亮你的人生。

Speakers 分享人:
Life Practitioners
生命匠人

23 August 2025, Saturday
10am - 11:30am
Hall 8, Concourse Level, PICC

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PUBLIC TALK | 公开讲座

THE BEST FAREWELL: LET LOVE REMAIN, NOT REGRET (Chinese Talk)

最好的告别:让彼此只有爱没有遗憾

(中文讲座)

Through his personal stories of end-of-life companionship, Yee Leong invites us to reflect on the value of understanding death from life and living with death in mind.

以量将会分享在善终场景中的亲身陪伴体验，让观众思考善终、善别及善生的重要性。

Speaker 分享人:

Fong Yee Leong
冯以量

Palliative Care Advocate
Senior Consultant, Xiao En Counselling & Support Dept
临终关怀推动者，
孝恩辅导与谘商部资深顾问

23 August 2025, Saturday
11:30am - 1pm
Hall 8, Concourse Level, PICC

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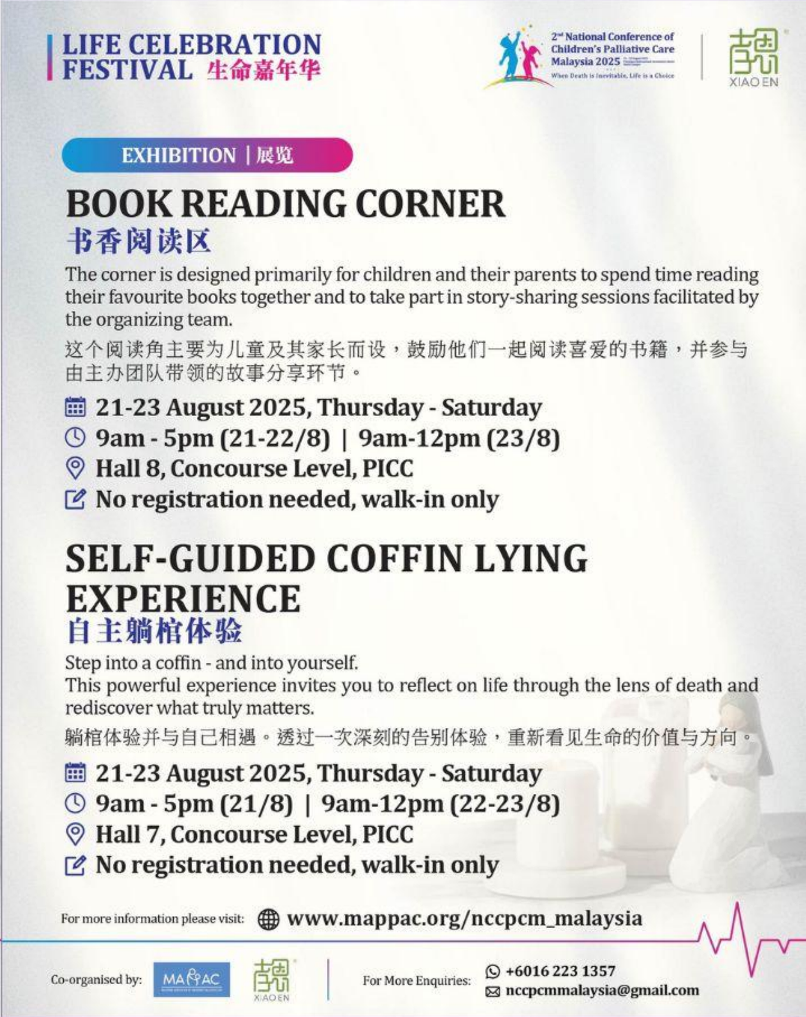

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EXHIBITION | 展览

BOOK READING CORNER

书香阅读区

The corner is designed primarily for children and their parents to spend time reading their favourite books together and to take part in story-sharing sessions facilitated by the organizing team.

这个阅读角主要为儿童及其家长而设，鼓励他们一起阅读喜爱的书籍，并参与由主办团队带领的故事分享环节。

21-23 August 2025, Thursday - Saturday
9am - 5pm (21-22/8) | 9am-12pm (23/8)
Hall 8, Concourse Level, PICC
No registration needed, walk-in only

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自主躺棺体验

Step into a coffin - and into yourself.
This powerful experience invites you to reflect on life through the lens of death and rediscover what truly matters.

躺棺体验并与自己相遇。透过一次深刻的告别体验，重新看见生命的价值与方向。

21-23 August 2025, Thursday - Saturday
9am - 5pm (21/8) | 9am-12pm (22-23/8)
Hall 7, Concourse Level, PICC
No registration needed, walk-in only

For more information please visit: **www.mappac.org/nccpcm_malaysia**

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Acknowledgement

We would like to extend our heartfelt gratitude to everyone who contributed to the success of this event.

First and foremost, we thank the Ministry of Health Malaysia (KKM), our co-organiser for their invaluable support and collaboration. KKM has been instrumental in making this event a reality.

We are deeply grateful to the committee members for their tireless efforts and commitment. Your guidance and expertise have been crucial in ensuring the smooth execution of every aspect of this event.

A special thank you to our volunteers whose enthusiasm and dedication have been truly inspiring. Your willingness to lend a helping hand wherever needed has not gone unnoticed.

We also extend our sincere appreciation to our sponsors. Your generous contributions have provided the necessary resources to make this event possible. Besides the earlier mentioned sponsors, we are thankful to:

Adventa Healthcare Sdn. Bhd.
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Tong Xin Training Centre
Yayasan WWRC

Puan Sri Mae Cheng
Ms. Ching Choo
Dato Kee
Mrs. Karen Kok
Ms. SL Leong
Ms. Ng Wei Yin
Mr. Tim Callaham
Mr. Joseph Yu
& those names are not mentioned here

Last but certainly not least, we thank all the participants. Your active engagement and participation have been the heart and soul of this event. We hope you found it enriching and enjoyable.

Thank you all once again and we shall meet again at the next NCCPCM.

Xiao En Group

Life Education: Preserving Eternal Memories

When we speak of sustainability, we often think of the environment. Yet in Malaysia, one leader demonstrates that true sustainability begins with humanity, especially when we learn from life and death.

Xiao En Group believes that funerals are not merely about completing rituals, but about education, companionship, and cultural continuity. With this conviction, it has become Malaysia’s first funeral institution to systematically promote Life Education, redefining the profession from service provider to social educator.

Under the leadership of Managing Director Dato Frank Choo, Xiao En has pioneered initiatives such as:

- **Grief counselling support for bereaved families**
- **The Silent Mentor programme, where body donors continue to inspire medical learning after death**
- **Ash burial, emphasizing humanity’s relationship with nature**
- **Life Educational outreach in schools and communities, using death as a lens to reflect on life**

“These are not add-ons,” stresses Dato Frank Choo. “As long as humanity exists, death is inevitable. Our role is to accompany families through grief while guiding them toward deeper values of gratitude and love.”

Rooted in filial piety and gratitude, Xiao En extends family ethics into enterprise and society. Safeguarding one family’s memory, in essence, preserves the cultural DNA of an entire community.

Today, Xiao En is not just a funeral service provider, but a pioneer transforming the space of death into a space of life education. By integrating life education, ecological care, and cultural continuity, it has awakened the essence of the industry and inspired a broader reflection: only by learning to say goodbye can we truly learn to live well.

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HOPE Healing & Meditation Center

HOPE Healing & Meditation Center is a sanctuary for holistic well-being, offering a safe and nurturing space to support your healing journey physically, emotionally, and spiritually. Rooted in the transformative practice of Pranic Healing, HOPE provides workshops, scannings, personal healing sessions and corporate trainings that empower individuals to take charge of their health using energy-based techniques.

Our services include Pranic Healing workshops, emotional healing, and aura scanning using GDV (Gas Discharge Visualization) technology, which offers insight into the body's energy field. These modalities are designed to help clear energy blockages, reduce stress, and promote clarity and inner peace.

As a proud member of the National Coalition for Mental Well-being, HOPE also works alongside various ministries, universities, and international institutions to promote mental wellness. We serve as both a training and consultancy center, bridging ancient wisdom with modern understanding.

Whether you're seeking inner stillness, emotional release, or a deeper connection to yourself, HOPE provides tools and guidance to support your transformation. At HOPE, healing is not just a destination—it's a lifestyle.

Follow us to stay updated on workshops, meditations, and events open to all.

HOPE

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- Mental
- Emotional
- Spiritual

Rooted in the transformative science of **Pranic Healing**, **HOPE** offers a safe, nurturing space to begin or deepen your healing journey. We provide **healing sessions, emotional clearing, aura scans using GDV technology, and certified Pranic Healing workshops**; all designed to help you clear energy blockages, reduce stress, and restore clarity and peace.

✓ Proud member of the National Coalition for Mental Well-being which collaborates closely with the Ministry of Health, Ministry of Home Affairs and other key institutions including WHO

Healing isn't just a moment — it's a lifestyle.

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Smile-Link Healthcare Global

Drs. Wong & Partners Dental Surgeons began in April 2001 in Sri Petaling, Kuala Lumpur, founded by Dato' Dr. Wong Ruen Yuan. As patient demand grew across Malaysia, Dr. Wong envisioned bringing care to communities rather than asking patients to travel. In 2010, he established Smile Link Dental Group to build a network of neighbourhood clinics. The group later evolved into Smile Link Healthcare Global Berhad, which was listed on Bursa Malaysia's LEAP Market on 23 April 2019—an achievement that reflects Malaysia's rising standards in private dental care alongside peers in Singapore and Thailand.

Today, Smile Link and Drs. Wong & Partners operate nearly 100 clinics nationwide. Our mission is to develop a private dental healthcare ecosystem—community clinics, specialist dental centres, and a future dental hospital—that complements the country's public system. As a prominent group practice, we are committed to nurturing young dentists, innovation, and delivering accessible, high-quality, patient-centred care.

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Drs. Wong & Partners Dental Surgeons

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Children's Health & Development Centre

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Dedicated Paediatric Oncology Services

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SUNWAY HEALTHCARE

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GDPMD No: MYG8151521 ☎1700 81 8769 1700 81 3343 hello@yikenmedical.com
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Dorothy Scents

Dorothy Scents is a wellness-inspired brand that blends tradition, elegance and nature into every hand-poured creation, inspired by the founder's grandmothers, Dorothy, each product is crafted with love – using a signature blend of soy and beeswax, certified essential oils, and thoughtful details that awaken the senses.

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Rooted in care and crafted with intention, our scents are more than fragrance – they're and invitation to pause, breathe and reconnect. Wherever life takes you, bring a little calm along with Dorothy Scents

Discover the calming power of scent. Our hand poured soy and beeswax candles, room mist and natural shower oils are crafted to promote relaxation and well-being - one breath at a time.

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Appendix 1:
Abstract Book

OP1

Perceptions of Adult Palliative Care Physicians on the Transition of Pediatric Palliative Care Patients to Adult Services

Fahisham Taib[1], Noor Hasimah Mohmad[2]

[1]Paediatric Department, Hospital Pakar Universiti Sains Malaysia, Kelantan, Malaysia, [2]Medicine Department, Hospital Raja Perempuan Zainab II, Kelantan, Malaysia

Corresponding author: Fahisham Taib

Email: fahisham@gmail.com

ABSTRACT

Objective: This survey investigates adult palliative care physicians' perceptions of the transition process for paediatric palliative care patients moving to adult services in Malaysia.

Methods: A descriptive cross-sectional study was conducted from May to June 2025. Adult palliative care physicians were invited to complete an online questionnaire developed from a literature review on transition challenges and provider preparedness in Malaysia.

Results: Eighteen physicians participated (mean age 44.6 years), predominantly from the government sector (72.5%) with over 10 years of experience (66.2%). Half reported no formal transition training, and 44.4% identified transition age as 16 years or younger. Participants expressed inadequate preparedness and insufficient knowledge of paediatric-onset chronic conditions. Key barriers included limited interdisciplinary collaboration and inadequate community infrastructure to support this vulnerable population.

Conclusion: The findings highlight significant gaps in infrastructure, provider preparedness, and multidisciplinary involvement, adversely affecting the quality of transitional care. Strengthening training, fostering interdisciplinary cooperation, and enhancing community resources are critical to improving transition outcomes for paediatric palliative patients.

Keywords: Transition care, Paediatric Palliative care, Adult Palliative care, Multidisciplinary team, Service

OP2

Childhood Mortality with Life Limiting Illness Based on Malaysia National Mortality Data 2014-2022

Chua Ker Yang[1], Nickson Tai Boon Khean[1], Sin Li Jie[1], Choong Yee Wan[1], Lee Chee Chan[1]
[1]Paediatric Department, Hospital Tunku Azizah Kuala Lumpur, Kuala Lumpur, Malaysia
Corresponding author: Ker Yang Chua
Email: keryang100@hotmail.com

ABSTRACT

Background: Paediatric palliative care (PPC) provides support for children with life limiting illness (LLI) and their family. PPC services is growing in Malaysia, but information on actual population need is lacking.

Objective: This study aimed to estimate the number of children with LLI by using national mortality data.

Methodology: A retrospective descriptive study using secondary data from Department of Statistics Malaysia (DOSM) was conducted on all paediatric deaths in Malaysia between January 2014 and December 2022. ICD-10 four-character-codes associated with LLI from previous studies were reclassified into three-character-codes, namely confirmed LLI codes or possible LLI codes based on whether all or some of the four-character-codes derived from the three-character-codes were LLI conditions. Confirmed LLI deaths (CLD) only included confirmed codes while possible LLI deaths (PLD) included both confirmed and possible codes.

Results: During the 9-year period, there were 54,887 deaths among children aged 18 years and below. 48,492 (88.3%) were medically certified deaths, of which 5,537 (11.42%) were CLD and 22,100 (45.57%) were PLD. There was a median of 599 (interquartile range, IQR: 591-627) CLD and 2,416 (IQR: 2,335-2,535) PLD annually. For CLD, majority of children were from ICD-10 category "neoplasms" (2,499, 45.1%) and "congenital malformations, deformations and chromosomal abnormalities" (1,488, 26.9%).

Conclusion: Almost half of the deaths amongst children may be attributed to LLI. PPC services can help to support these children and their family. However, many children with palliative care needs who are living were not included in this calculation.

Keywords: Child mortality, Palliative, Paediatric, Health service needs and demand, ICD-10

OP3

Empowering Parents: A Caregiver Workshop for Families of Children with Severe Neurological Impairment

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ABSTRACT

Objective: The primary objective is to identify the specific challenges encountered by families of children with severe neurological impairment (SNI), as well as to evaluate caregivers' competencies and confidence in addressing these challenges following participation in the workshop.

Methods: The workshop was organized as a comprehensive one-day program with participants selected from a registry of patients with severe neurological impairment (SNI) actively receiving follow-up care at the combined neuro-palliative clinic. Pre-workshop online forms identified caregivers' key challenges, while post-workshop evaluations measured improvements in participants' skills and confidence following the training session.

Results: Between October 2023 and March 2025, four workshops were conducted, involving 34 participants with diverse caregiving experiences. 27 participants completed the post-workshop feedback and reported that the workshops were highly beneficial and relevant to their daily caregiving routines. More than half (51.8%) reported an improved understanding of caregiving, while 37% especially valued the peer sharing sessions. Additionally, 14.8% gained confidence in Ryles tube insertion, 7.4% learned new physiotherapy techniques, and 3.7% found dental care sessions useful. Looking ahead, 15% wanted further training in physiotherapy and massage, and 11% were interested in learning more about emergency care and stress management. Others highlighted their desire for workshops on social welfare, advanced nursing, and pain relief strategies to further support their caregiving roles.

Conclusion: In conclusion, the workshop meaningfully enhanced caregivers' confidence and practical skills. It also improved emotional and mental well-being, demonstrating the power of targeted educational support for families facing the profound challenges of severe neurological impairment.

Keywords: Caregivers, Neurological Manifestations, Palliative medicine, Hospice care, Education

OP4

Evaluating the Efficacy and Sustainability of the New Bereavement Care Plan in The Paediatric Department, Hospital Seberang Jaya Over a 14 Month Period

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ABSTRACT

Background: Complicated grief affects up to 10% of bereaved individuals and 40% of bereaved parents, who often require psychosocial support. Bereavement care helps mitigate mental health risks in up to 50% of caregivers. However, only 23.6% of parents attended the pediatric bereavement clinic in 2023.

Objectives: This study aimed to evaluate clinic attendance after implementing an enhanced bereavement care strategy and assess the program's sustainability by identifying challenges faced by healthcare providers. Secondary objectives included assessing parental mental health using the DASS-21 questionnaire and evaluating satisfaction with the updated care model.

Method: A retrospective cohort study was conducted at the Pediatric Clinic from April 2024 to May 2025. It involved bereaved parents whose children died in neonatal and pediatric wards. The revised care plan included a memory-making box (with footprints and photographs), bereavement pamphlets, and structured reminder calls. During clinic visits, parents completed the DASS-21 and a satisfaction survey and were offered supportive amenities. Healthcare staff completed an online perception survey.

Results: Clinic attendance increased to 56%. Most healthcare workers viewed the revised model as beneficial and identified key barriers and solutions. Among parents who attended, the majority reported normal stress, anxiety, and depression levels, and unanimously described the session as helpful and satisfactory.

Conclusion: These findings highlight the value of structured, compassionate bereavement interventions and support the long-term feasibility of an enhanced care model for grieving parents.

Keywords: Complicated grief, Bereaved parents, Bereavement care, Efficacy, Sustainability

OP5

Development and Pilot Testing of a Questionnaire Assessing Caregiver's Knowledge, Attitude and Practice (KAP) on Opioid Use in Pediatric Palliative Care (PPC) at a Tertiary Hospital in Malaysia

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ABSTRACT

Objective: The purpose of this study to develop and pilot test a comprehensive assessment tool to evaluate knowledge, attitude, and practice (KAP) of caregiver on opioid use in children for pain management in Pediatric Palliative Care at Hospital Tunku Azizah Malaysia

Methods: This KAP of caregiver was a guided self-administered questionnaire and consisted of 17 knowledge, 9 attitude and 6 practice items. After items generation, it was assessed the content validity by an expert panel. The revised questionnaire was further pre -- tested. This pilot study was a cross -sectional survey and recruited 35 caregivers from patient received opioid for pain treatment by PPC team in Hospital Tunku Azizah, Malaysia. Item analysis, construct validity and internal consistency were examined.

Results: Two sub-domains were constructed for knowledge, three factor solutions for attitude and two factor solutions for practice domains respectively. All items retained in the questionnaire as the important of all items to be included. Internal consistency was good to excellent for knowledge (KR20 = 0.63), attitude (CA = 0.73), practice (CA = 0.64) domains. The finalized KAP caregiver questionnaire after analysis remained contained of 32 items with 17 knowledge, 9 attitude and 6 practice items.

Conclusion: KAP caregiver was an adequately valid and reliable questionnaire which can serve as an assessment tool to evaluate the knowledge and beliefs among caregivers of patient received opioids for the pain management in Malaysia

Keywords: Caregivers, Knowledge Attitudes Practice, Opioid Analgesics, Pediatric Palliative Care, Pain Management

OP6

A Comparative Study on the Knowledge of Medical Officers Regarding Advance Care Plan (ACP) Discussions in Hospitals With and Without Paediatric Palliative Care Services

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ABSTRACT

Background: Advance Care Planning (ACP) is essential in paediatric palliative care (PPC), guiding treatment in line with family values. However, ACP is underutilized, especially in settings without formal PPC services.

Objectives: To assess and compare medical officers' (MOs) knowledge of ACP in paediatric settings, identify perceived barriers, and evaluate self-reported confidence and experience in ACP discussions.

Methods: A cross-sectional survey was conducted among MOs in six hospitals in Penang---two with PPC services and four without. A validated questionnaire measured ACP knowledge, barriers, and attitudes. Descriptive and inferential statistics were used for analysis.

Results: MOs in PPC-supported hospitals had higher correct response rates on ACP timing (56.0% vs. 41.8%), components (68.2% vs. 53.7%), and ethical principles (36.4% vs. 25.4%), though differences were not statistically significant ($p > 0.05$). Key barriers reported included lack of training (88.7%), time constraints (68.4%), unclear hospital policy (64.7%), and fear of upsetting families (67.7%). While most MOs agreed that ACP improves quality of care (90.2%) and is a shared responsibility (93.2%), only 22.6% felt confident initiating discussions.

Conclusion: Medical officers recognize the value of ACP but face significant knowledge and confidence gaps, especially in hospitals without PPC services. Targeted training and clearer institutional support are needed to improve ACP integration in paediatric care.

Keywords: Advanced Care Planning, Palliative Care, Paediatrics, Terminal Care, Health Knowledge Attitudes Practice

PP1

A Descriptive Review on Children Receiving Specialised Paediatric Palliative Care at Hospital Shah Alam

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ABSTRACT

Background: Specialised Paediatric Palliative Care service at Hospital Shah Alam (PPC HSAS) was established in keeping with the National Palliative Care Policy and Strategic 2019-2030. It delivers inpatient care and runs 2 monthly multidisciplinary team (MDT) clinics. Additionally, children and families are supported by Malaysian Children Hospice for home-based holistic care.

Objective: This review describes the referral characteristics, symptom prevalence and role of MDT in specialised symptom management.

Methods: Retrospective review on children receiving care under PPC HSAS aged 0-18 years from December 2023 until December 2024 was conducted. Data was extracted from the PPC database, department census and hospital electronic Health Information System(e-HIS). Data was recorded and analysed using Excel.

Results: A total of 20 children (17 males, 3 females) with a median age of 6.5 years (range: 2 months to 17 years) received care. 90% lived within 15 km of the hospital and 85% had PaPaS score of ≥15. Neurological conditions were most common (55%), with pain (22%) and dystonia (19%) as prevalent symptoms. 65% had at least ≥3 symptoms. The MDT service addressed the physical, social, emotional and spiritual well-being of the children. Mean consultation duration for each patient was 24.4 minutes. At follow-up, 60% remained under care, 20% were discharged, 5% transitioned to adult services and 15% of families received bereavement support.

Conclusion: MDT approach was seen as essential in addressing complex, multifaceted needs of children with life-limiting conditions and holistic support required by their families. Regular service reviews and further studies are needed to evaluate the outcomes of MDT interventions.

Keywords: Paediatric palliative care, Symptom, Specialised, Multidisciplinary, Family

PP2

A Descriptive study on Perinatal Palliative Care Services at Hospital Tunku Azizah, Kuala Lumpur

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ABSTRACT

Background: Perinatal palliative care service (PPCS) provides support for infants and families when there is a diagnosis of severe life limiting illness either before or after birth. PPCS services have been established in Hospital Tunku Azizah, Kuala Lumpur (HTAKL) since March 2020.

Objective: To describe the characteristics of referral and outcome of infants receiving PPCS at HTAKL.

Methods: A retrospective observational study was conducted on all antenatal referrals for PPCS from March 2020 until February 2024. Data collected include referral information, clinical outcome, and services provided.

Results: During the study period, PPCS received 29 antenatal referrals. Majority (89.6%) were Malay mothers. The median gestational age on referral was 32 weeks 3 days with the earliest being at 27 weeks 5 days. The main antenatal diagnoses were chromosomal abnormalities (11, 37.9%), abnormal brain or spinal cord development (4, 13.8%), congenital anomaly (4, 13.8%), and renal disorders (3, 10.3%). On delivery, there were 8 stillbirths. Among the 21 infants who were born alive, 4 died in the labour room while 10 died in NICU. The remaining 7 children were discharged home with feeding support and medications. Services provided by PPCS include labour room visit by PPCS team (7), family conference (8), anticipatory grief counselling (3), memory making (18), and home visit/hospice (3).

Conclusion: PPCS supported families of infants with severe life limiting illnesses in navigating care, symptom management and bereavement support.

Keywords: Perinatal, Palliative care, Prenatal diagnosis, Family support, Life limiting

PP3

The Use of the Pediatric Palliative Screening Scale (PaPaS) Score as A Routine Screening Instrument in Pediatric Oncology Patients: A Single-center Descriptive Cross-Sectional Study

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ABSTRACT

Introduction & Objective: The Pediatric Palliative Screening Scale (PaPaS) Score is a screening tool used to determine the focus of care. Pediatric palliative care (PPC) is a vital component of pediatric oncology service, and the use of PaPaS may improve usage adherence and prompt provision of PPC. We conducted this study to assess the utilization of PaPaS score in pediatric hematology-oncology ward.

Methods: This is a descriptive cross-sectional study conducted since August 2023. Data are obtained by medical record review of each inpatient episode from every patient with oncologic diagnoses. Patients with non-neoplastic diagnoses are excluded. PaPas Score is determined by on-duty hospitalist at the time of inpatient admission and authorized by the attending pediatric hemato-oncologist. A score of 10 or more indicated the need of consultation to PPC team. Data are reported using descriptive statistics, reported as median due to uneven distributions of data.

Results: A total of 25 data points from 12 patients (5 females, 7 males) are included. The most common diagnoses are acute leukemias (75%), with other diagnoses including Burkitt's lymphoma, dysgerminoma, and neuroectodermal brain tumour. The median of the whole PaPaS score data points is 10, with 0 the lowest and 35 the highest data points, and 0 and 32 as the lowest and highest patient's personal PaPaS score respectively. 13 data points scored at least 10.

Conclusion: Routine use of PaPas Score in pediatric oncology patients is integral and important to ensure that palliative care may be provided in a timely manner.

Keywords: Cross-sectional Studies, Palliative Care, PaPaS Score, Pediatrics, Pediatric Oncology

PP4

Ethics in Paediatric Palliative Care: A Case Study from a District Hospital in Sarawak

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ABSTRACT

Objective: To explore ethical conundrums in formulating an advanced care plan (ACP) for a child with severe cerebral palsy (CP), focusing on the clinicians' dilemma and parental decision-making.

Methods: We studied a 13-year-old girl with spastic quadriplegic CP secondary to hypoxic-ischemic encephalopathy and moderate-to-severe intellectual disability. Her case was analysed using normative ethical principles to identify key issues in paediatric palliative care.

Case Presentation: The child did not attend school because of complex needs and was primarily cared for by her aunt while both parents worked. After a two-year interruption in follow-up, she presented following a five-minute choking episode, which required 20-minute CPR at home by the mother, a nurse. She was admitted for non-invasive oxygen therapy and observation. Despite persistent lung collapse, she was discharged at the parents' request with a "Do Not Resuscitate" (DNR) order following discussion. At the three-month follow-up, the child showed notable functional improvement (GMFCS level III). The DNR order was revoked, and broader care planning was discussed.

Discussion / Conclusion: This case highlights the ethical complexity of initiating DNR orders during acute illness without a thorough assessment of premorbid function. Guidelines emphasise that DNR should be based on anticipated medical futility, not a disability or perceived burden. The mother's dual role as clinician and parent introduced further ethical challenges. Additionally, the child's broader needs --- education, sibling support, caregiver respite, and spiritual care --- although no easy solution, must be addressed. Holistic, dynamic, and family-sensitive care planning is essential in paediatric palliative care.

Keywords: Advanced Care Plan, Spastic Quadriplegic Cerebral Palsy, Choking episode, Do Not Resuscitate, Holistic care

PP5

The Burden of Palliative Care for Children with Congenital Heart Disease: a Cardiac Center Experience in Malaysia

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ABSTRACT

Objective: The aim of this review is to understand the burden of Paediatric Palliative Care (PPC) for complex congenital heart disease in a paediatric cardiac centre, Malaysia.

Methods: This retrospective descriptive study examined all patient referrals to the Paediatric Palliative Care Service at Hospital Sultan Idris Shah, Serdang, from January 2022 to May 2025. Data were extracted from existing hospital medical referral records. Descriptive statistics were used to analyze and summarize the characteristics of referred patients and referral patterns.

Results: A total of 62 referrals were received, of which 58% were cardiac-related. The number of referrals has been increasing each year: 10 cases in 2022, 17 cases in 2023, and 24 cases in 2024. There were 11 referrals from January to May 2025. Among the cardiac patients, most have complex heart disease with no surgical options, inoperable residual lesions, cardiomyopathy, and severe comorbidities. The purposes of referral are mainly symptom management, advanced care planning, caregiver support, coordination of care across multiple specialties, equipment support, and discharge care.

Conclusion: Despite the short duration of the pediatric palliative care service in HSIS, there is an increasing number of patients requiring palliative care. Advances in the diagnosis and treatment of patients with congenital heart disease have resulted in an overall decrease in mortality. However, these patients experience long-term morbidities and uncertainty in disease trajectory, thus requiring palliative support.

Keywords: Paediatric Palliative Care, Paediatric, Congenital Heart Disease, Paediatric Cardiology, Palliative Care

PP6

Buttons That Speak: Connecting with Adolescents and Young Adults in Palliative Care

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ABSTRACT

Introduction: Adolescents and young adults (AYA) with cancer are unique as they transition toward independence while coping with a life-limiting illness. Communication with this group can be challenging due to emotional vulnerability, evolving identity and the need for autonomy. The "Button Game" is a technique commonly used in paediatric palliative care to facilitate communication in children, and it can be beneficial in AYA setting. This case report illustrates the use of "Button Game" as means of communication with a young adult patient.

Method: Case Report

Case: We first met this patient when she was 23 years old. She was diagnosed with metastatic osteosarcoma of the left tibia and fibula 2 years ago. Despite undergoing surgery, chemotherapy and radiotherapy, her disease progressed, resulting in spinal cord compression and bedbound. She became socially withdrawn, and the community palliative care nurses encountered difficulty in establishing rapport with her. The Button Game was introduced to facilitate communication, allowing her to express her fears, hopes and values. This approach fostered trust, improved engagement and enabled us for more effective symptom management. A close relationship developed between the patient and the community palliative care team. She died six months later, but her final months were characterised by better communication, shared decision-making and holistic support for her and her family.

Conclusion: This case demonstrates the use of "Button Game" in communication with the AYA population. Such an approach can bridge communication gaps and enhance person-centred care in this unique population. Through this case, we wish to highlight the importance of "Button Game" for communication regardless of age groups.

Keywords: palliative care, paediatric palliative care, communication, adolescent and young adults, button game

PP7

Dietitian-Led Nutritional and Palliative Care in an Infant with DiGeorge Syndrome and Congenital Heart Disease: A Case Report

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ABSTRACT

Objective: To evaluate the impact of individualized nutritional intervention on growth outcomes, biochemical stability, and quality of life in a critically ill 4-months-old infant diagnosed with DiGeorge syndrome and complex congenital heart disease, with eventual transition to palliative care.

Methods: An individualized nutrition care plan was initiated with energy and protein targets of 90 kcal/kg/day and 3.5 g protein/kg/day. Due to severe feeding intolerance, sequential formula modifications were implemented, beginning with anti-regurgitation (AR) formula, followed by an amino acid-based formula and later a lactose-free formula. Whey protein isolate (wpi) and cereal fortification were introduced to support catch-up growth. Monitoring included regular anthropometry, dietary intake records, and biochemical markers such as urea, sodium, and potassium. As prognosis declined, nutritional goals were redefined to prioritize comfort, minimal intervention, and caregiver support, aligning with palliative care principles.

Results: Initial weight gain was suboptimal due to persistent gastrointestinal symptoms, feeding intolerance, and cardiorespiratory instability. Following nutritional adjustments, gradual improvement was observed, with weight increasing from 2.8 kg to 5.28 kg over nine months. Peak intake reached 136.3 kcal/kg and 3.84 g/kg protein. However, biochemical instability persisted, indicating ongoing catabolism and clinical deterioration. Nutrition care was subsequently reoriented toward symptom relief, including management of abdominal distension, vomiting, and fatigue, while emphasizing comfort feeding and meaningful family interactions.

Conclusion: Individualized nutrition strategies can support growth and symptom control in complex paediatric cases. In progressive conditions like DiGeorge Syndrome, integrating palliative nutrition---focused on tolerance, comfort, and family-centered goals---is essential for preserving dignity and enhancing quality of life.

Keywords: DiGeorge Syndrome, Heart Defects Congenital, Nutrition Therapy, Palliative Care, Quality of Life

PP8

Common Medications Used by Neuropalliative Clinic in Hospital Tunku Azizah, Kuala Lumpur

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ABSTRACT

Background: Neuropalliative care in paediatric patients addresses symptoms that impact quality of life in children with severe neurological conditions which are life-limiting or life threatening. Optimal medication use is critical for symptom control and overall care. In 2019, neuropalliative service was introduced in Hospital Tunku Azizah, Kuala Lumpur (HTAKL), a children's and women's hospital.

Objective: To present the common medications used by neuropalliative clinic in HTAKL.

Methods: Patients with severe neurological impairment have many symptoms requiring pharmacological intervention. They receive multiple medications for a symptom, which compounds when a patient has multiple symptoms. Pharmacists play a role to reduce polypharmacy, prevent possible drug-drug interaction and reduce pill burden.

Results: Eighty-six patients attended neuropalliative clinic from 1 May 2024 until 30 April 2025. Majority were boys (51.2%) and Malay (73.3%). Median age of patients was 11.0 years (Interquartile range, IQR 7.3-15.8). Patients received a median of 8 (IQR 6-9) different medications, with a maximum of 13 medications. Patients mainly required medications for seizure (94.2%), constipation (88.4%), dystonia (77.9%), gastro-oesophageal reflux disease (GERD) (67.4%), hypersalivation (36.0%), and insomnia (11.6%). Median number of concurrent medications received per symptom was 3 for seizure, as well as 2 for constipation, dystonia, and GERD.

Conclusion: Neuropalliative patients receive many concurrent medications. All parties need to evaluate the need for each medication to ensure compliance, improve symptom control and reduce pill burden.

Keywords: Palliative medicine, Polypharmacy, Nervous System Disease, Paediatric, Malaysia

PP9

Multidisciplinary Nutritional Rehabilitation and Challenges in Nutritional Management of Syndromic Infants with Severe Malnutrition: A Case Series Involving Integration of Dual-Centre Care

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ABSTRACT

Objective: To demonstrate the structured application of the Nutrition Care Process (NCP) in managing a syndromic infant with chronic severe malnutrition, highlighting the importance of cross-institutional collaboration, continuous dietetic care, and palliative-informed decision-making.

Methods: A 1-year 4-month-old male infant with a confirmed homozygous pathogenic variant in the FILIP1 gene, severe laryngomalacia, and multiple comorbidities was admitted for four weeks of nutritional rehabilitation. Initial nutrition assessment revealed significant weight loss (from a maximum of 4.4 kg to 3.35 kg), persistent regurgitation, and poor feeding tolerance via nasogastric tube. Nutrition Diagnosis: Inadequate protein-energy intake related to feed interruption and physiological intolerance as evidenced by persistent feeding issues limiting progression. Nutrition Intervention focused on gradual energy and protein escalation using combination of enteral feeding, including anti-regurgitation, isocaloric, and modular. Energy intake was increased from approximately 90 to 180 kcal/kg/day. Feeding plans were continually adjusted based on tolerance, gastrointestinal symptoms, and family-centred goals. Following ENT surgical intervention, patient was transferred to another centre. Dietitians from both institutions coordinated care to ensure feeding continuity, symptom control, and goal alignment. The patient's mother, central to decision-making, declined invasive options like TPN or PEG due to quality-of-life concerns.

Results: Despite minimal weight gain, patient achieved clinical stability and improved feed tolerance. Dietetic collaboration ensured continuity and rapid adaptation of feeding strategies. Feeding provision post-surgery-maintained energy intake at 150--180 kcal/kg/day.

Conclusion: This case highlights the value of the NCP, interdisciplinary teamwork, and coordinated care across centres. Dietitians play a critical role in supporting complex, syndromic infants through personalized, palliative-informed nutrition planning.

Keywords: Malnutrition, Laryngomalacia, Nutrition Therapy, Energy Intake, Patient-Centered Care

PP10

Advanced Care Planning in Paediatric Palliative Care Patients at Hospital Tunku Azizah

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ABSTRACT

Objective: Advance care planning (ACP) is an important process for children with life limiting conditions. It helps families and healthcare providers talk about values, beliefs, and wishes to guide medical decisions and future care but is not legally binding.

Methods: ACP discussion by paediatric palliative care (PPC) team of Hospital Tunku Azizah (HTA) follows a structured, step-by-step approach. It focuses on eight parts: personal details, patient and family members involved in the discussion, diagnosis, symptoms and signs to expect during emergencies, personal resuscitation plan, end-of-life care preferences, preferences during life, and the agreement. Discussion starts by exploring what matters most to the child and family, followed by preferences for future care, and finally goals of care---ranging from full intervention to comfort-focused care. ACPs are reviewed 6-12 monthly or when the child's condition changes.

Results: There were 83 deaths among paediatric patients referred to PPC team HTA between January 2024 and June 2025. ACP was completed in 69 cases (83.1%), while 56 (81.2%) of them had the latest review of ACP within one year of death. All families decided not for cardiopulmonary resuscitation and intubation. 98.6% had decided for maximum intensity of care in the general ward. 66 (95.7%) families had discussed preferred place of death.

Conclusion: ACP coverage has room for improvement. Annual review and awareness of ACP are key to making ACP a normal part of children's care.

Keywords: Palliative medicine, Paediatric, Advance care planning, Cardiopulmonary Resuscitation, Malaysia

PP11

Preferred Place of Death: Part of Advance Care Planning for Paediatric Palliative Care Patients

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ABSTRACT

Background: Preferred place of death (PPOD) is a key component of advance care planning (ACP) in discussions with families of children facing life-limiting illnesses during end-of-life care.

Objective: To describe the preferred and actual place of death among patients under the Paediatric Palliative Care (PPC) Unit at Hospital Tunku Azizah (HTA), Kuala Lumpur.

Methods: ACP discussions are a core aspect of managing patients with life-limiting illnesses within the PPC Unit at HTA. PPOD is addressed with patients and families when they are ready. Families opting for home death require community support from either hospice services or the domiciliary team.

Results: Between January 2024 and June 2025, there were 83 deaths among patients under the care of the PPC Unit at HTA. Of these, 69 patients (83.1%) had undergone prior ACP discussions, and 66 (95.7%) had discussed their preferred place of death. Approximately half (51.5%) were undecided about the location. Among those who expressed a preference, 9 of the 11 who chose hospital death (81.8%) and 12 of the 21 who chose home death (57.1%) were able to fulfil their wishes. Of the 32 patients who died at home, 20 (62.5%) received support from hospice or domiciliary services.

Conclusion: PPOD discussions are a vital part of PPC planning, aligning care with the values and preferences of patients and their families. However, some patients are unable to realise their choices due to various challenges. Strengthening community support and enhancing ACP implementation may increase the likelihood of fulfilling patients' and families' end-of-life wishes.

Keywords: Death, Advance Care Planning, Paediatric, Palliative Care, Home care services

PP12

Patient-controlled Analgesia by Paediatric Palliative Care Unit in Hospital Tunku Azizah

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ABSTRACT

Background: Patient-controlled analgesia (PCA) can assist in better control of pain. Patients would get continuous infusion of analgesic and self-initiated immediate bolus of analgesic when needed. This is useful for children with palliative care needs because pain is one of their major symptoms.

Objective: To describe the PCA service provided by paediatric palliative care (PPC) unit in Hospital Tunku Azizah (HTA).

Methods: PCA services for uncontrolled pain was started by PPC unit HTA for oncology ward since 2019. It is guided by an existing standard operating procedure. Referred patients will be assessed for cognitive capabilities and competency in using the PCA machine. A medical assistant will set up the PCA machine based on settings from the PPC specialist. Patients are monitored for pain score and complications. PCA will be discontinued when pain is improved.

Results: From 2021 till 2024, there were 11 patients who received PCA services. Median age of patients was 13.4 years (Interquartile range, IQR: 11.8-16.2), with the youngest being 8.9 years old. Majority were Malay (63.6%), male (54.5%), and in unstable phase (81.8%). All patients received PCA morphine. Median pain score improved from 8 (IQR: 7.5-8.5) to 0 (IQR: 0-2.5) with a median drop of 7 (IQR: 5.5-8). Side effects include nausea (18.2%), itchiness (9.1%), and urinary retention (9.1%), but did not cause PCA to be discontinued. Median PCA duration was 72 hours (24-120).

Conclusion: PCA services by PPC unit HTA was able to improve pain score for uncontrolled pain with limited and acceptable side effects.

Keywords: Patient Controlled Analgesia, Paediatric, Palliative Care, Chronic Pain, Morphine

PP13

Occupational Therapy Recommendations for Aids, Adaptation and Assistive Equipment for Paediatric Palliative Patients at Hospital Tunku Azizah Kuala Lumpur

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ABSTRACT

Background: Paediatric palliative care patients experience problems affecting quality of life, which could be improved via aids, adaptations, and assistive equipment (AAA). Occupational Therapy (OCCT) providers assist by recommending AAA which support the children to achieve optimal functional independence and reduce caregiver burden. Despite its significance, there is limited data on OCCT recommendations and equipment implementation within the Malaysian hospital setting.

Objective: To describe paediatric palliative patient referrals to Occupational Therapy (OCCT) in Hospital Tunku Azizah Kuala Lumpur (HTAKL) for Aids, Adaptive and Assistive Equipment (AAA) as well as the recommendations given.

Methods: A retrospective descriptive study was conducted on paediatric palliative patients referred for AAA to the OCCT unit at HTAKL from January 2021 until December 2024. Data was extracted from OCCT census lists and from the electronic Hospital Information System.

Results: There were 31 patients referred for AAA during the study period. Majority were male (54.8%), Malay (90.3%) and referred from the neuropalliative clinic (67.7%). OCCT recommendations and education was given for mobility aids (18), bathing aids (9), training adaptive devices (4), and toileting aids (1). However, only 17 (53.1%) of the recommended AAA were obtained, specifically 11 (61.1%) for mobility aids, 3 (33.3%) for bathing aids, 2 (50.0%) for training adaptive devices and 1(100.0%) for toileting aids. The majority of AAA obtained were funded by external sources (94.1%).

Conclusion: The acquisition rate of recommended aids can be improved, highlighting the need for improved funding access and follow-up mechanisms to ensure timely provision.

Keywords: Occupational Therapy, Palliative, Paediatric, Activities of Daily Living, Self-Help Devices

PP14

The Last Act of Love: A Young Lady's Decision to Hold Her Own Living Funeral

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ABSTRACT

Objective: Death has always been a taboo topic that is avoided. With the rise in young patients receiving life-limiting diagnoses, it is increasingly important for society to destigmatize death and encourage open conversations about life and loss. We report a case of a terminally-ill young patient who held a living wake prior to her passing.

Case report: A 25-year-old Chinese female was diagnosed with a rare aggressive form of ovarian cancer in 2022 which metastasized by late 2023. She was given a prognosis of 6 months and started on palliative chemotherapy. She subsequently organized a "living funeral" with help of a local hospice - a get-together with close ones to celebrate her life journey and show appreciation. The patient passed on 2 weeks after her living wake.

Discussion: A living funeral can be seen as a celebration of one's life journey and allows for expression of gratitude, healing past wounds and finding closure. It encourages individuals to speak openly about death, leading to deeper understanding and acceptance of the natural cycle of life, reducing fear and anxiety. Individuals can also express their wishes for after-life care, and such transparency can alleviate the burden on loved ones who might struggle to make such decisions during a time of grief.

Conclusions: Living funerals can be a testament to a life well lived and leave a legacy of love. The growing trend of living funerals offers an alternative approach to embracing end of life, and shining light at the end of the tunnel.

Keywords: Living funeral, End-of-life care, Terminally-ill, Grief, Bereavement

PP15

Memory Making Using Footprints for Paediatric Palliative Patients in Hospital Tunku Azizah

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ABSTRACT

Background: Memories and mementos could be important for families of patients with paediatric palliative care (PPC) needs, especially after the patients have passed on. The PPC unit of Hospital Tunku Azizah (HTA) assists with memory making through footprints using ink or clay.

Objective: To describe the service of memory making by PPC unit HTA.

Methods: During consultation sessions with patients and family, a choice of memory making through footprint is offered. The selection of materials or type of footprint is based on the age, size and clinical condition of the patient. Colour selection is based on the child's gender and parental preference. This footprint is designed by staff or by the family, with occasional additions of poetry written by the family members. Clay footprints take longer to be prepared, leading to longer duration before handing over to the family.

Results: From November 2022 until June 2025, there were 52 episodes of memory making using footprints. Majority of patients were from paediatric cardiology discipline (27, 51.9%), Malay (37, 71.2%) and female (33, 63.5%). There were 51 ink footprints and 2 clay footprints produced. 2 footprints were made post-mortem. There were no major challenges during the making of the footprints.

Conclusion: Footprint making is a feasible option for memory making.

Keywords: Palliative Care, Paediatric, Advance care planning, Object Attachment, Malaysia

PP16

Understanding the Profile and Motivation of Volunteers in Children's Palliative Care: A Descriptive Study in MAPPAC

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ABSTRACT

Objective: This study aims to describe the demographic characteristics, interests, availability, and motivations of individuals who volunteer in children's palliative care services in Malaysia.

Methods: A descriptive analysis was conducted based on volunteer registration data from 2023 to 2025, collected by the Malaysian Association of Paediatric Palliative Care (MAPPAC). Data included demographics (age, gender, location), type of volunteer interest, availability, relevant skills, work background, and reasons for joining.

Results: A total of 205 volunteers were registered, predominantly female (82.4%), with the majority aged 30--49 years (58%). Most were from Selangor (48.8%) and Kuala Lumpur (23.4%). Volunteers expressed interest in general support (42.9%), homecare (23.9%), and events (26.3%). Preferred volunteering time was daytime (51.2%), with weekends being the most favored days (51.2%). Key skills included training & education (57.6%) and event organization (44.4%). Volunteers came from diverse work backgrounds, notably sales/marketing (11.7%) and NGO/charity (6.3%). Top reasons for volunteering were contributing back to society (50.7%), and gaining knowledge and experience (19%).

Conclusion: Children's palliative care volunteers in Malaysia are predominantly women aged 30--49 with strong interests in education, events, and community service. Understanding their profiles and motivations helps tailor recruitment, training, and retention strategies, enhancing service delivery and volunteer engagement in pediatric palliative care.

Keywords: Palliative Care, Paediatric, Volunteers, Hospice Care

PP17

The Last Chapter: Expectations and Insights on End-of-Life Care from Healthcare Professionals

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ABSTRACT

Objective: To explore the expectation and perspective of healthcare professionals on principles of good death based on TFHCOP (The Future of Health and Care of Older People) towards paediatric patients in Malaysia.

Methods: We did a cross-sectional study on 50 medical officers working across Malaysia. We used a 15-questionaire questions based on the paper entitled: A good death: perspective of muslim patients and healthcare providers in which we compare the view of paediatrics medical officers and non-paediatrics medical officers. We used descriptive statistics to analyse the questionnaire responses.

Results: More than 90% of Paediatrics Medical officers agree with the majority of the questions however we notice a lower percentage about 85% of non- paediatrics Medical Officers agree on the questions posed. Interestingly, both groups scored less than 70 % on question No.2 (To be able to retain control over what happens) and No.15 (A good death is a death accepted by the relative).

Conclusion: This study highlights a broad consensus among Malaysian medical officers on key elements of a good death, with minimal variation between paediatric and non-paediatric professionals. Factors including limited exposure to paediatric patients and involvement in end of life care may be the reason for discrepancy among the two groups studied. Nevertheless, areas such as autonomy and family acceptance show less agreement, suggesting a need for further dialogue and culturally sensitive approaches in paediatric end-of-life care.

Keywords: Good Death, Patient autonomy, End of life care, Palliative care, Malaysia

PP18

"In Their Shoes": Understanding Caregiving Needs from Parents of Children Receiving Palliative Care in Our Community

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ABSTRACT

Background: Paediatric palliative medicine (PPM), is a niche subspeciality in Malaysia. It has been striving, despite limited resources to provide care for children and families faced with life limiting and threatening conditions. Malaysian Children's Hospice (MCH) was first established in June 2023 under the Malaysian Association of Paediatric Palliative Care (MAPPAC) which enabled a multidisciplinary model to complement home-based care. Caregivers of children with palliative care needs often face significant challenges in providing long-term comprehensive care. This study aims to identify the key support and service needs of these caregivers for the future development of targeted interventions and supportive services in our community.

Objectives: This study described the perceived caregiving needs from parents of children receiving palliative care in our community through services provided by the Malaysian Children's Hospices; focusing on physical, emotional, social, and practical support.

Methodology: A survey was conducted between 2nd December 2024 to 2nd January 2025, collecting feedback from caregivers of children receiving community palliative care support from the Malaysian Children's Hospices, regarding current services and other desired support. Thematic analysis was used to identify recurring needs and preferences. Caregivers of patients referred to 2 branches of MCH (Kuala Lumpur and Klang) from 1st June 2023 till 31st December 2024 were included.

Results: A total of 20 responses were recorded and analysed. Majority of caregivers were involved with patients' care at home in between 6 to 10 years. The most frequently reported needs included home visits from healthcare professionals, access to medical equipment and care supplies, social welfare support, access to support therapies, and mobility/transport services. Caregivers also emphasized the importance of training and knowledge related to pain and symptom management at home, as well as opportunities for their children to engage in social interaction/therapeutic activities in child development and having access to respite care.

Conclusion: Comprehensive and holistic support systems are essential for families caring for children with complex medical needs in community palliative care. Addressing the identified needs can improve the well-being of both caregivers and children, and promote better outcomes.

Key words: Children, Caregiver, Palliative Care, Hospice

PP20

The Shape of Goodbye: Exploring Grief and Meaning-Making Through Clay in Clinical Review

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ABSTRACT

Objective: To explore how integrating play therapy techniques, such as symbolic clay work, in clinical death review sessions supports emotional processing and reflective practice among paediatric nurses in palliative care.

Methods: Structured monthly death review sessions were conducted with paediatric nurses who provided end-of-life care. Each session included facilitated reflection, a timeline review, and the use of expressive play therapy tools, such as clay modeling, as non-verbal mediums for exploring emotions, unresolved thoughts, and care dynamics. Sessions aimed to support grief acknowledgment, reduce moral distress, and foster team-based empathy and insight.

Results: In one session, one nurse reflected on the case of a young boy with a terminal illness who had initially resisted medical care and later opened up through weekly home-based play therapy. As part of the reflective activity, the nurse chose to create a sushi out of clay, a food the child loved and often talked about during visits. She gently shaped the pieces in silence, later sharing, *"This sushi is him. And maybe it's us, too."* She described how the clay helped her feel grounded, allowing her to symbolically revisit the child's journey. She acknowledged the guilt she carried for not being able to ease his pain sooner, but gradually accepted that the support given was neither "more nor less"; it was what he could receive when he was ready. The reflective process allowed her to reframe her experience with compassion, moving from self-judgment to meaning-making.

Conclusion: Integrating creative mediums such as clay into clinical death reviews offers nurses a tangible and emotionally safe outlet to process grief and complex emotions. This case illustrates how symbolic play, which is traditionally used with children, can be equally valuable for healthcare professionals navigating loss. In paediatric palliative care, where emotional labor is high, such integrative debriefing methods support staff well-being, build emotional resilience, and deepen the team's understanding of each child's unique journey. These sessions serve not just to reflect on care outcomes but also to honour the human connections formed.

Keywords: Palliative Care, Play Therapy, Nursing Staff, Reflective Practice, Clinical Competence, Symbolism, Grief

PP21

Paving the Way for Dignity in Health Care for Children with Serious Illnesses in the West of Nepal

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ABSTRACT

Objective: To explore the perspective of children with serious illnesses (SI) and healthcare professionals (HCPs) on dignity in Nepal. To develop a Nepal-specific dignity model for children with SI and to develop a practical training module on dignity in healthcare in Nepal

Methods: In-depth interviews with 15 children (>12years), 15 caregivers; and 4 focus group discussions each consisting of 8 HCPs in three hospitals in Gandaki Province using the guideline based on the dignity model for dying adults and the dignity model for terminally ill children. Recordings will be transcribed. The analysis will follow deductive (thematic) and inductive (grounded theory) processes to adapt and contextualize the previously developed dignity model in the Nepalese context.

Results: Preliminary findings show empathetic communication, quality time and the attitude of HCPs play a major role in preserving dignity for these children. The HCPs have the realization that they fall short in providing care with dignity due to time constraints, set up etc.

Conclusions: Despite the centrality of dignity in palliative care, there is little understanding in the healthcare context in Nepal. This study aims to explore the lived experiences of children with SI, their families, and HCPs to develop contextual model of dignity which will act as building block in developing training module for HCPs on caring for children and their families with dignity. It will further support in developing relevant policies and procedures

Keywords: Dignity, Children with serious illness, Pediatric palliative care

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