



## Training and Education Days – Summary of Year 1 days

### Foundation PEOLC Study Day 1

#### Existing resources/regional/national training:

Many tertiary centres offer foundation level training for their own staff and staff in hospitals and community settings with whom they work on a regular basis. Some children's hospices also offer palliative care training. The quantity and quality of this training is highly variable and practice is inconsistent across and between regions. There is no agreed national standard for defining foundation or advanced levels of training in palliative care, however the Royal College of Nursing competency framework provides a broad guide as to more basic and advanced competencies. There will be regional variation in how PEOLC is supported within regions therefore there is a need for training to be bespoke at regional network level.

#### Overview:

For many children and families palliative care is delivered over a period of months to years. The staff with whom they have the most contact during this time are not palliative care specialists, but community and local hospital nursing staff. The delivery of palliative care causes anxiety for many nurses regardless of the setting in which they work or their position in their respective teams. This becomes more apparent when a child's condition changes, and it becomes more likely that the child is entering the end stages of their life. Concerns include how to manage symptoms, how to manage the different devices used to deliver medications in an end-of-life setting, talking with children and families about their situation and managing expectations, what happens around the time of death and immediately afterwards, care of the child's body after death and ongoing support for families.

The day is designed to be an introduction/refresher for all staff to clarify what palliative care is and to give an overview of various elements of paediatric palliative care that relate to their day to day work. Further days are planned to support those working at a more senior level across the region, or those who would like to learn more about specific aspects of paediatric palliative care.

#### Aims:

Session	Aims/objectives
<b>What is paediatric palliative care</b>	<ul style="list-style-type: none"> <li>• Understand what paediatric palliative care is, parallel planning, symptom management, ethical decision making, advance care planning</li> <li>• Understand who is eligible to receive paediatric palliative care</li> <li>• Understand who delivers paediatric palliative care</li> <li>• Understand the benefits of early involvement of paediatric palliative care services</li> <li>• Explore communication with families</li> <li>• Importance of self care</li> </ul>
<b>Symptoms and symptom management plans</b>	<ul style="list-style-type: none"> <li>• Review the unique and holistic aspects of symptom experience</li> <li>• Explain the process of assessing pain in children and young people</li> <li>• Understand basic principles of pain assessment and management approaches</li> <li>• Be able to interpret a symptom management plan</li> </ul>
<b>Syringe Drivers</b>	<ul style="list-style-type: none"> <li>• Understand what a syringe driver is and when it may be used</li> </ul>



	<ul style="list-style-type: none"> <li>• Understand intravenous and subcutaneous infusions in end of life care, including suitable sites for subcutaneous infusion devices</li> <li>• Understand issues around mixing drugs and compatibility</li> <li>• Understand how to prepare an infusion</li> <li>• Understand how to set up the syringe driver</li> </ul>
<b>Advance Care Planning and ReSPECT</b>	<ul style="list-style-type: none"> <li>• Understand what an advance care plan is</li> <li>• Be able to recognise when it might be appropriate to begin an advance care plan</li> <li>• Understand how advance care plans are completed.</li> <li>• Understand how ReSPECT/DNACPR fits with advance care plans</li> <li>• Understand who the advance care plans are shared with and where they are stored</li> </ul>
<b>Introduction to loss, grief and bereavement. Communication around lead up to a death and difficult conversations</b>	<ul style="list-style-type: none"> <li>• Understand that defining the end-of-life period can be difficult and is variable</li> <li>• Understand how to communicate with family members around a child dying</li> <li>• Explore how to discuss potential treatments aimed at disease control rather than cure</li> <li>• Appreciate what 'normal dying' looks like</li> <li>• To be able to describe the essential components of good care at end of life</li> <li>• Understand which interventions may help and provide comfort and which may not, and how to discuss these</li> <li>• Consider staff reactions/responses, understand the importance of self care</li> <li>• Understand what to do immediately after the child has died</li> <li>• Consideration of how staff express condolences to family following the child's death</li> </ul>
<b>Legal procedures post death</b>	<ul style="list-style-type: none"> <li>• Understand the difference between verification of death and certification of death</li> <li>• Understand the difference between expected and unexpected death.</li> <li>• Understand when a death may be referred to a coroner</li> <li>• Understand the process and timings of verification and who can do this</li> <li>• Understand the process and timings of certification and who can do this</li> <li>• What to do if the child is to be cremated</li> <li>• Understand the process and timings for registering the death</li> <li>• Understand the review processes post death – Medical Examiner, CDRM, CDOP</li> </ul>
<b>Organ and tissue donation</b>	<ul style="list-style-type: none"> <li>• Understand under which circumstances organ and tissue donation can take place</li> <li>• Understand the different timescales and options for place of death for organ and tissue donation</li> <li>• Understand which organs and tissues may be donated</li> <li>• Understand that there may be some exemptions to donation</li> <li>• Understand that referral for donation does not mean that donation is guaranteed</li> <li>• Understand that families may change their mind at any time</li> </ul>
<b>Mortician</b>	<ul style="list-style-type: none"> <li>• Understand the processes and care provided by mortuary staff</li> <li>• Understand practical and administrative processes</li> <li>• Understand how the body is cared for post death</li> </ul>
<b>This is our hospice ...</b>	<ul style="list-style-type: none"> <li>• Understand the different services and support available from the three children's hospices covering the Wessex region.</li> </ul>



<b>presentations from 3 regional hospices</b>	<ul style="list-style-type: none"> <li>• Be able to refer to a children's hospice for an appropriate child.</li> <li>• Understand how children's hospice interact with statutory and third sectors.</li> <li>• Compare and contrast approach used by different hospices across the region.</li> </ul>
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### Feedback from study day 2023:

This training day was developed prior to the rest of the WCYAPCN training days. Therefore feedback is in a slightly different format and restricted to post-study-day data only.

General free text feedback received:

- Thank you all for a well-planned informative day, I learnt so much new information today, this study day has kept me engaged at all stages. Brilliant.
- Many thanks to the knowledgeable and passionate speakers for a hugely valuable and informative day which will inform and improve my practice going forward.
- I have found today so interesting; the day really showed a great insight to all aspects relating to palliative care and end of life.
- Really good day. Very informative. Delivered at a very good level too. Wide range of topics covered.

Suggestions for improvement:

- Focus on staff support and experiences (this will be covered in day two of the foundation training)
- More focus on the community perspective.
- Less use of powerpoint for one or two presentations.
- Content of some sessions felt to be too much for some delegates. Others appreciated the depth of information.
- Requests for hard copy of symptom management plan and CYPACP for reference.
- Requests for practical experience with syringe drivers, advance care plans and symptom management (note this is delivered in the other network days).

Session specific feedback (scores from 1-5)

Session	Rating	Comment Summary (generic comments removed eg 'informative' 'enjoyed')
<b>What is Paediatric Palliative Care</b>	5	Great context to background and definitions and goals of palliative care. Very informative overview of what palliative care really entails. Very passionate speaker, interesting and useful to my role. Very clear and easy to understand. More interaction/games rather than just power point. A useful start to the day to help introduce palliative care and dispel the myths. Really interesting and a good insight to what is covered in palliative care. Very good informative session on what palliative care is / the common misconceptions.
<b>Case Introduction</b>	4.3	Interesting case. Clearly presented case study. Clearly spoken, case study helpful as it was a lived experience. Too much information covered in such a small amount of time.



		<p>Helped me relate real life situation to information being delivered.</p> <p>A great way of learning and putting things into a relatable context. Caseload was very clearly and comprehensively delivered.</p> <p>A sensitive and interesting case study helped relate the situation to the course.</p> <p>Really interesting case study. Very good overview of case, delivered in a very empathic way. Very difficult session to listen to but can understand the value and depth of information provided.</p>
<b>Symptoms &amp; Symptom Management Plans</b>	4.7	<p>Useful to focus on pain and assessment.</p> <p>Helpful for future patients. Very informative.</p> <p>Really good presentation, very informative and thought provoking.</p> <p>Really interesting to pick apart symptoms and all the aspects of pain. Passion for job role clear.</p> <p>Very knowledgeable – again too much content attempted to be covered, meaning I zoned out at times, death by Power point.</p> <p>Had limited knowledge about medications used, feel more knowledgeable now.</p> <p>Excellent explanation of common symptoms and managing these.</p> <p>A great delivery of how to look at symptom management, really made me think. Very useful – refreshing different types of pain and assessment.</p> <p>Such an informative session – good to discuss non pharma logical treatment.</p> <p>Very interesting to see this from a doctor's point of view.</p> <p>Lots of present with limited time. Good overview of symptom management.</p> <p>Very informative. Lots of information but all very useful. Like the hard copy of the management plan.</p> <p>Really engaging. Explained in an easy to understand way.</p> <p>A lot of info but all useful, well-tailored for understanding. A bit too oncology specific, would have liked more general medical. Quite PowerPoint heavy.</p>
<b>Syringe Drivers</b>	4.5	<p>Good overview on how to use a reminder on what doesn't mix.</p> <p>Don't really use on ward but still interesting.</p> <p>We don't use this on the ward but was good to hear about them.</p> <p>Good information session.</p> <p>Pitched at the right level for my current use of syringe drivers. Practical session.</p> <p>Great explanations on how to use equipment.</p> <p>A very useful session. I feel much more confident in understanding syringe drivers and subcut access /placement.</p> <p>Useful to know what practically critical.</p> <p>Helpful to discuss syringe drivers in / out of hospital. Really useful to have info on compatible meds and where we can find this info in practice.</p> <p>Working in hospital use different syringe drivers.</p> <p>Good up to date info. Practical session to see syringe driver in use would be helpful. Really useful, info easy to understand.</p>
<b>Advance Care Planning + RESPECT</b>	4.5	<p>Linked prompts suggested for open questions.</p> <p>Did not know there was a RESPECT form, also wasn't sure we could fill them out which was helpful.</p> <p>It was interesting, possibly the session could have been a little longer – query example 'complete document'.</p> <p>Loved the slido interactive bits.</p> <p>New information, learning RESPECT when to start ACP.</p>



		<p>A valuable session in building confidence to conduct ACP's and early introduction of this where possible.</p> <p>I found this so interesting and really relevant and will definitely look at ACP's more.</p> <p>Good to discuss ACP's and to reassure those less confident that there can be completed / most beneficial if completed by those that know the family best.</p> <p>Good focus on community involvement.</p> <p>May be helpful to complete some of the ACP together.</p> <p>Precise and to the point, easy to understand. Would be useful to have a paper copy to see up close.</p>
<b>Preparing for Imminent Death</b>	5	<p>Difficult topic but delivered very well.</p> <p>Passionate speaker with useful information of how to speak to families and siblings when a child has died.</p> <p>Practical and useful advice which I can implement into practice.</p> <p>Very informative. More interaction would be lovely.</p> <p>Will watch podcasts Katheryn Mannix as death make me feel uncomfortable.</p> <p>Useful advice and guidance around talking about death with families and children.</p> <p>A good way to see how to choose ways to speak with families and best phrases / words to avoid / use.</p> <p>Excellent process to use / what not to sign.</p> <p>Really sensitive session. Kate delivered this so well.</p> <p>There could have been more focus on how staff are affected.</p> <p>So much that could be discussed but great insight.</p> <p>Hard to hear as sensitive topic but provided useful examples.</p>
<b>Legal Procedures Post Death</b>	4.2	<p>Very useful key points as recently had a situation on ward where no one knew what to do.</p> <p>Very informative. We do not come across death as often, so we are always unsure on what to do.</p> <p>Interesting to know about the legal stuff.</p> <p>Dry BUT vital to know and understand. Speaker made the subject bearable.</p> <p>Very informative. I enjoyed it very much.</p> <p>Useful in helping to understand CDOP procedure further and what happens post-death.</p> <p>Although Tim thought we would struggle, it was interesting.</p> <p>Useful. Very informative.</p> <p>I know these procedures are often aspects that nurses are concerned about following a death, so was useful to cover.</p> <p>There is so much useful information, this could easily be a 2 day course to discuss further. Everything was great.</p>
<b>Organ &amp; Tissue Donation</b>	4.6	<p>Great overview on role and what we can think about.</p> <p>Informative. Did not know you had to be ventilated to be able to be an organ donor. Was an eye opener.</p> <p>Very informative, something that I've never learnt about previously.</p> <p>Clear and well presented.</p> <p>Lots of new information I knew little about this before today, thought it would be more straight forward.</p> <p>Rachel was highly knowledgeable and informative and delivered a great session.</p>



		<p>I found this interesting and has made me think about having conversations with my family.</p> <p>Really interesting session, very minimal experience of organ donation so this was good. Also, shocked at the actual number of individuals who are suitable for donation (I thought the number was far higher).</p>
<p><b>The role of the Mortician</b></p>	<p>4.6</p>	<p>Really useful to understand processes after we've transferred.</p> <p>Very informative. Did not know anything about what happened in the mortuary, so very helpful.</p> <p>Interesting, informative. It's useful to understand more about the process following a patient death.</p> <p>Really informative. Must be difficult to present due to topic. Learnt a lot of new things.</p> <p>Detailed insight in to roll of staff in mortuary, what they do / can offer families.</p> <p>Despite being nervous Catrin was great, well done. Really useful information well delivered.</p> <p>A good insight into what happens in mortuary and the services available for families.</p> <p>Informative session, minimal experience of mortuary care so this was interesting to know.</p> <p>Presentation was beautiful. There can be a negative connotation re morticians, but it is such an important job.</p>
<p><b>This is our hospice (3x short sessions)</b></p>	<p>4.6</p>	<p>Great insight into the facilities that are available.</p> <p>Great insight into what each hospice offers.</p> <p>Powerful video, great understanding how care /support impacts family.</p> <p>All talks were brilliantly put together, very passionate about everything they do. The Chestnut Tree House videos were very moving. A great insight to how hospice runs / works.</p> <p>Really helpful to cover other hospices available as I know we often suggest Naomi House but forget about other options available. Very difficult video.</p> <p>Good to see other hospices.</p> <p>Very helpful, lots of useful information.</p> <p>Really useful to know about other options for families.</p> <p>Nice to see what the hospices look like and impact on families.</p> <p>Great insight into what each hospice offers.</p> <p>Tearjerker video.</p> <p>Feel I have a better understanding of what hospices offer.</p> <p>All talks were brilliantly put together, very passionate about everything they do. The Chestnut Tree House videos were very moving. A great insight to how hospice runs / works.</p> <p>Interesting to hear about the different services that each hospice provides and the different facilities available.</p> <p>Good to see other hospices.</p> <p>Really useful to know about other options for families.</p> <p>Great insight into what each hospice offers.</p> <p>Learnt new information, good reminder of what is on offer especially the criteria grid.</p> <p>All talks were brilliantly put together, very passionate about everything they do. The Chestnut Tree House videos were very moving. A great insight to how hospice runs / works.</p>



		Good overview of Naomi House and Jack's Place. Didn't appreciate age range of Jack's Place so that was interesting to find out. Really useful to know about other options for families.
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## Plan for training day 2024:

TBC (in discussion)

## Competency mapping:

### Royal College of Nursing Competencies:

#### Section 2

#### Communicating Effectively

L01: (Levels 2-8) Communicate effectively with children requiring palliative care and their families, using a range of different aids.

- Communicate simple information verbally or in writing to other members of the team, by adapting communication to ensure information is shared well, and escalate to other team members if required.
- Demonstrate an ability to communicate with various ages, stages of development and cognitive abilities, by adapting communication to meet the needs of different children and make use of other colleagues if there are issues e.g. SALT.
- Demonstrate ability to enable child/family to communicate fears and concerns and empower families to make informed decisions in conjunction with others, building rapport and trust with families at times of distress.
- Demonstrate ability to assist with managing barriers to effective communication, and adapt to manage fears or anxieties, simplify content and use communication aids as needed to enable children's understanding.
- Demonstrate an ability to adhere to local policies ensuring notes are factual and punctual and ensure that minutes of meeting are disseminated.

L02: (Levels 5-8): Meet both comprehensive and specific complex communication needs of children and their families across the continuum of care.

- Demonstrate ability to adapt communication to meet the needs of families and children dependent on age and abilities.
- Demonstrates ability to contribute to appropriate communication of assessing, planning, evaluation and documenting of care for children with palliative care needs.
- Demonstrate an ability to display understanding and sensitivity around conversations at an appropriate time and pace.
- Demonstrate an ability to apply knowledge of communication and be able to support children and their families through times of uncertainty.
- Demonstrate an ability to discuss treatments, care options and symptom management plans at an appropriate cognitive level.



- Demonstrate awareness of psychological, emotional and spiritual issues when communicating with children and their families.
- Demonstrate an ability to work with others and contribute to MDT planning and decision making.
- Demonstrate ability to have self-awareness, make use of team and wider supervision offers, showing awareness of own needs and coping strategies.

### Section 3

#### Multidisciplinary Holistic Care

L01: (Levels 2-8) Provide holistic nursing care for children and families.

- Demonstrate the delivery of delegated nursing care, within defined guidelines and protocols following the prescribed care plan.
- Demonstrate gathering accurate information that informs nursing care, and which contributes to changes in prescribed care or symptom management plan.
- Demonstrate awareness of activities of daily living for a child with palliative care needs.
- Communicate simple information to other members of the multidisciplinary team.
- Assist with assessment and planning of care, guided by protocols and with support from registered practitioners.
- Deliver, evaluate and record care with supervision from a registered practitioner to address health related problems/needs.
- Identify the optimum quality of life for the individual child and their family.
- Demonstrate an understanding of the implications of palliative care for the child and the wider family.

L02: (Levels 5-8) Provide comprehensive holistic and evidence-based nursing care to children with complex palliative care needs across the care pathway.

- Demonstrate appropriate clinical judgment, in consultation with others, to provide evidence-based nursing care that meets the complexity of the child's palliative care needs.
- Demonstrate partnership working with other sectors and agencies including: health, education, social services and voluntary sector.
- Demonstrate therapeutic relationships with children and their family to assist their informed choices for care and treatment.
- Provide child and family with choices where possible, and recognise the impact these choices can have on quality of life, for example, remaining in hospital or staying at home at end of life.
- Evaluate outcomes of care and makes alterations appropriate to the clinical situation.
- Facilitate discussions and act as an advocate to children and families with palliative care needs.

### Section 4

#### Identify and Manage Symptoms





L01: (Levels 2-8) Contribute to symptom management by: Identifying and describing severity of symptoms, recognising pain and/or discomfort, accessing appropriate support from senior staff.

- Provide opportunities for children to voice and or demonstrate experiencing pain/discomfort.
- Recognise and report changes in child's behaviour and condition
- Follow organisational policy and individualised care plans including related to medicines management
- Recognise signs of physical and emotional distress
- Use pain and other symptom assessment tools.
- Assist in providing non-pharmacological symptom management such as massage, music therapy and positioning.

L02: (Levels 5-8) Contribute to development of symptom management plans by participating in discussion with primary carers, identifying a range of physical and psychological symptoms, assessing and evaluating care.

- Collaborate with the team around the child to manage symptoms
- Follow symptom management plan.
- Assess, deliver, evaluate and record care and symptom management
- Initiate discussion about symptom management.
- Recognise unstable signs and symptoms
- Participate in clinical supervision and peer review

## Section 5

### Grief Loss and Bereavement

L01: (Levels 2-8) Recognise signs of distress in the child and family members and enable access to appropriate support.

- Discuss with a registered nurse/practitioner of distress in a child or family member
- Follow local organisational guidelines related to appropriately supporting children, families and colleagues before, at the time of and after death.
- Support and actively listen to grieving family members and carers.
- Respect an individual's beliefs, community, culture, spirituality and religion.
- Assist with age-appropriate play to engage children in conversation to encourage them to express their feelings and emotions with regards to loss.

L02: (levels 5-8)

- Behave with appropriate sensitivity and professionalism consistently.
- Use listening skills to support individuals in their grief.
- Access relevant support for children and families and refer appropriately.
- Implement advance care plan, and review this in partnership with the child and their family with support of an experienced palliative care nurse/practitioner.

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