

# Learning Pack: Paediatric Palliative Medicine

This learning pack can be used for local teaching and for individual reading and reflection. Several activities have been designed and they have been mapped to the RCPCH Progress curriculum.

Feel free to use any or all of this pack in your department. If you wish, you can reflect on the learning activity and upload to your e-portfolio.

Comments/feedback to Mehrengise Cooper

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## **When to refer a child to Paediatric Palliative Medicine**

### **Activity: Case Based Discussions**

#### **Objectives:**

1. Know the definition and understand the scope of paediatric palliative care
2. Know the four groups of life-limiting and life-threatening conditions
3. Understand parallel planning and the relationship between palliative care and disease-directed care
4. Demonstrate an awareness of the wide range of professionals included in the multidisciplinary team approach of paediatric palliative care

#### **Small Group Discussion (30 minutes)**

##### **Facilitator Instructions:**

- Facilitate a small group discussion regarding referral to PPM
- Draw on personal experiences of the group for collective learning

##### **Participant Instructions:**

- Read the following cases in a small group and discuss whether you think they would each benefit from referral to palliative care
- Where you think referral might be beneficial, consider what kind of support a palliative care team might be able to offer
- Think about which members of the MDT would be best placed to help in each case

#### **Case 1**

Molly is a 12-year old girl recently diagnosed with osteosarcoma of her left femur.

#### **Case 2**

David is an 8 year old boy with Duchenne Muscular Dystrophy who has recently become wheelchair bound.

#### **Case 3**

Susan is a 36-year old woman who is 3 months pregnant with her first child. She has just had her dating scan which revealed that the foetus has anencephaly. Susan does not wish to terminate the pregnancy.

#### **Case 4**

Lila is 14 year old girl with severe spastic cerebral palsy, secondary to birth asphyxia. She has global developmental delay, is exclusively PEG-fed, suffers from epilepsy and requires full-time care. In the last six months Lila has had four hospital admissions with respiratory infections, two of which have required stays in intensive care.

#### **Further reading and discussion (20 minutes)**

- Read the following article: [Harrop E, Edwards C. \(2013\). How and when to refer a child for specialist paediatric palliative care. Archives of Disease in Childhood - Education and Practice. 98:202-208](#)
- Review the following guide: [Together for Short Lives. \(2018\). A Guide to Children's Palliative Care.](#)

Now review the cases and consider which category of life-limiting and life-threatening conditions each case falls into. Go back through your answers and consider which layer of paediatric palliative care might be suitable for each case.

## Activity: Role Play

### Objectives:

1. Be able to build up rapport with a patient or carer
2. Demonstrate an ability to initiate a conversation about referral to paediatric palliative care
3. Deal with the emotional difficulties of such a conversation

### Role Play Activity (30-60 minutes)

#### Candidate Instructions:

- You are the Senior Registrar involved with the case
- For each of the cases above initiate a conversation with the child's parents to introduce the concept of paediatric palliative care
- You have 10 minutes for the scenario

#### Facilitator Instructions:

##### Assess

- Appropriate introduction and structured conversation
- Establishes a good rapport
- Demonstrates empathy and compassion throughout
- Exploration of parental thoughts regarding palliative care
- Evidence of understanding that palliative care for children is not just at end of life but is for any child with a life-limiting or life-threatening condition
- Summarises conversation and arranges a follow up conversation

##### Feedback

- Provide a structured debrief for the group
- Enable trainee to self-reflect on performance
- Encourage the group to recall similar experiences for collective reflection
- Generate shared learning points for the group
- Use the [RCPCH MRCPC Clinical Anchor Statements](#)

#### Discussion Points:

- Good palliative care involves parallel planning
- Find out what the parents feel and want- establish where they are in their journey and what their priorities are
- Avoid discussing end of life care or advanced care planning at this early stage

## **Pain management in Paediatric Palliative Medicine**

### **Activity: Case Based Discussions & Prescribing Practice**

#### **Objectives:**

1. Understand the principles of pain management in palliative care
2. Be able to safely prescribe initial and maintenance opioids
3. Be familiar with the indications and practicalities of syringe drivers
4. Demonstrate an awareness of commonly encountered side-effects of opiates

#### **Group Discussion and Prescribing Practice (30-45 minutes)**

#### **Facilitator Instructions:**

- Work through the following cases with a small group
- Utilise real prescription charts to demonstrate safe prescribing of unfamiliar drugs
- Discuss the group's previous experience of pain management in a palliative context
- Ideally ask your local pharmacist to assist with facilitation

#### **Case 1**

12 year old Molly presents to her local hospital with a few months history of left leg pain, with associated lethargy and weight loss. She is noted to have a swollen left thigh on examination and has difficulty mobilising due to pain. Her initial investigations include an MRI which suggests an osteosarcoma of her left femur.

Molly has been admitted to the ward, pending transfer to a tertiary centre and you have been asked by the nursing team to review her due to ongoing pain despite regular paracetamol and ibuprofen. Molly weighs 34kg and has no known drug allergies.

***Prescribe some additional pain relief for Molly.***

After a few days of titration, her pain is controlled on 5mg Oramorph 4 hourly, with an additional 5 breakthrough doses of 5mg Oramorph.

***Prescribe a suitable longer acting formulation.***

#### **Case 2**

15 year old Tyler has a diagnosis of metastatic rhabdomyosarcoma which has been resistant to treatment. His condition has been slowly deteriorating over the last few weeks, and he has reached a stage where his parents and oncology team feel he is near the end of his life. Tyler and his family have chosen to spend his last days in his local hospital, where he knows the team well, and feels comfortable.

Tyler was previously on 60mg MST BD with 10mg Oramorph breakthrough to control significant pain. However, he is no longer able to take his oral medications easily. You have been asked by the ward team what other options are available.

***Prescribe Tyler's ongoing analgesia.***

### Case 3

8 year old Aaliya has recently relapsed ALL. She has been started on regular oramorph for disseminated painful disease, but is suffering from severe constipation, unresponsive to escalating movicol doses. The nursing team asks you for your advice.

**Prescribe Aaliya appropriate therapy.**

#### Discussion Points:

- Initiation of analgesic therapy involves use of the WHO analgesic ladder
- It is appropriate to start a short-acting opioid such as Oramorph as per BNFC doses
- A regular background dose should be prescribed as well as a breakthrough dose
- Following 24-48 hours on initial doses the regimen can be titrated
- If >2 breakthrough doses have been required in 24 hours, an increase in background morphine is required. This is calculated by summing the initial daily background morphine with the breakthrough morphine used over 24 hours
- This dose can be delivered as slow-release morphine or MST given every 12 hours
- It is still important to write up a breakthrough dose which is  $\frac{1}{6}$  of the total morphine dose given a maximum of 4 hourly
  
- Towards the end of life, SC syringe drivers are an ideal way to deliver a combination of medications continuously
- The prior 24 hour dose of oral morphine should be halved to calculate the SC dose
- Breakthrough doses are calculated similarly to be  $\frac{1}{6}$  of the total SC dose 4 hourly
  
- Side effects common to opiates include:
  - Constipation-common side effect which needs to be anticipated upon starting opiates and managed promptly; may require an opioid switch
  - Pruritus- more common in children than adults; responds better to ondansetron than antihistamines; may require an opioid switch
  - Nausea and vomiting- less common in children than in adults
  - Respiratory depression- unlikely if opioid dose is titrated appropriately
  - Sedation- usually improves after a few days of therapy initiation
  - Agitation- may occur in younger children
  
- A combination of movicol disimpaction regimes and stimulant laxatives can be used to target constipation, as well as a consideration of an opioid switch, e.g. to a fentanyl patch, which is less constipating
- Several other factors also contribute to constipation in such cases: inactivity, poor muscle tone, poor diet, inadequate fluid intake, unfamiliar environment, etc.
- Remember that enemas should not be used without discussion in patients on chemotherapy as there is a risk of gram negative sepsis in neutropenic patients
- Oxycontin/ Oxycodone are good alternatives to morphine, and fentanyl patches are a first line alternative for patients that cannot tolerate oral opiates.

#### Resources:

[APPM. \(2020\). The Association of Paediatric Palliative Medicine Master Formulary 5th Edition.](#)  
[GOSH, UCLH and the Royal Marsden. \(2018\). Paediatric Haematology and Oncology: Supportive Care Protocols.](#)  
[Together for Short Lives. \(2016\). Basic Symptom Control in Paediatric Palliative Care. The Rainbow Children's Hospice Guidelines.](#)

## **Symptom control in Paediatric Palliative Medicine**

### **Activity: E-learning Module**

#### **Objectives:**

1. An understanding of common PPM symptoms other than pain
2. To include respiratory, gastro-intestinal, constitutional, neurological, psychological, dermatological and haematological symptoms
3. How to manage common symptoms, and practice safe prescribing

#### **E-learning Module (45 minutes)**

In small groups or individually:

- Register at [International Children's Palliative Care Network: elearning](#)
- Work through the module: Symptoms other than Pain in Paediatric Palliative Care

#### **Resources:**

Discuss any unexpected answers and review relevant guidelines and useful aides:

- [APPM. \(2020\). The Association of Paediatric Palliative Medicine Master Formulary 5th Edition.](#)
- [Together for Short Lives. \(2016\). Basic Symptom Control in Paediatric Palliative Care. The Rainbow Children's Hospice Guidelines.](#)

## **Breaking bad news**

### **Activity: Communication Scenarios**

#### **Objectives:**

1. Understand the challenges involved in breaking bad news to families
2. Demonstrate an ability to initiate conversations about Advanced Care Plans (ACP)
3. Deal with the emotional difficulties of such a conversation

#### **Role Play Activity (30-60 minutes)**

##### **Case 1**

Jack is a 6 year old boy who has presented to A&E with new onset bruising. On further exploration he has had a 2 week history of lethargy and weight loss. On examination he is pale with widespread petechiae and bruising, he also has hepatosplenomegaly. Jack's initial full blood count demonstrates pancytopenia and an urgent blood film confirms the presence of blasts.

#### **Candidate Instructions:**

- You are the Paediatric SHO/ Registrar Oncall during Jack's presentation
- Talk to Jack's parents about the results of the blood film and his likely diagnosis
- You have 10 minutes for the scenario

#### **Parent Instructions:**

- You have been concerned about Jack's new bruises and tiredness
- You believe he may have an infection or something easily treatable
- Jack is a previously well boy with no past medical history
- You are unprepared for a potential diagnosis of malignancy
- Your father-in-law has recently passed away from pancreatic cancer
- You become very emotional at the mention of cancer/ malignancy
- You want to know the next steps for Jack in terms of investigations and treatment
- You do not want to tell Jack anything about the possible diagnosis

#### **Facilitator Instructions:**

##### Assess

- Appropriate introduction and structured conversation
- Exploration of parental ideas, concerns and expectations
- An accurate and jargon-free explanation of pancytopenia and blasts
- Explicit communication of the likely diagnosis of cancer/ leukaemia
- An understanding of the next steps, including transfer to tertiary services, bone marrow biopsy and likely initiation of chemotherapy in a specialist centre
- Checks parental understanding and summarises conversation

##### Feedback

- Provide a structured debrief for the group
- Enable trainee to self-reflect on performance
- Encourage the group to recall similar experiences for collective reflection
- Generate shared learning points for the group
- Use the [RCPCH MRCPC Clinical Anchor Statements](#)

## Case 2

Lila is 14 years old with spastic cerebral palsy, secondary to birth asphyxia. She has global developmental delay, is exclusively PEG-fed, suffers from epilepsy and requires full-time care. In the last six months Lila has had four hospital admissions with respiratory infections, two of which have required stays in intensive care. Following step-down from a recent PICU admission, a meeting has been arranged to discuss Lila's ongoing care.

### Candidate Instructions:

- You are the Paediatric Consultant/Senior Registrar attending
- Talk to Lila's parents about her current clinical situation and ongoing care plans
- Initiate a discussion about Advanced Care Plans (ACP)
- You have 10 minutes for the scenario

### Parent Instructions:

- Lila is your only child, and you have dedicated your life to caring for her
- You want her to have the best quality of life possible, but are concerned with the frequency with which she has been admitted to hospital this winter
- You do not think Lila can cope with another PICU admission
- When ACP is mentioned, you are unsure what this means, but are open to a discussion- you would like more community support including hospice care
- If DNACPR is mentioned you become upset and say you are not ready
- You request another meeting in a few weeks including your community paediatrician who knows Lila well

### Facilitator Instructions:

#### Assess

- Appropriate introduction and structured conversation
- Exploration of parental thoughts regarding an ACP
- Consideration of the use of palliative care teams and hospice support
- Discussion of resuscitation and emergency treatment plans if appropriate
- Evidence of empathy and compassion throughout conversation
- Summarise conversation and provides a clear follow-up plan

### Discussion Points:

- Good palliative care involves parallel planning
- Find out what the parents feel and want- establish where they are in their journey
- Encourage involvement of the child, and ensure all key MDT members are present
- Remember- planning is a process, consisting of several conversations
- An ACP can empower families to voice their wishes, provide control in emergency situations and help achieve a 'good' death
- Review the below resources as a group and consider the further points which would need to be discussed in completing an ACP for appropriate patients

### Resources:

[National Institute for Health and Clinical Excellence. \(2016\). End of life care for infants, children and young people with life-limiting conditions: planning and management. NICE Guideline 61](#)

[Together for Short Lives \(2018\). Family Factsheets: Care Planning in Advance](#)

[Mack JW, Feudtner C, Hinds PS. \(2012\). Communication and Decision Support for Children with Advanced Cancer and Their Families. \*American Society of Clinical Oncology Education Book\*. 32:637-42](#)

## **Advanced Care Planning**

### **Activity: Part Task- Complete an Advance Care Plan (ACP)**

#### **Objectives:**

1. Become familiar with ACP paperwork
2. Understand the types of information which are relevant for an ACP
3. Recognise some of the challenges professionals face in completing ACPs

#### **Facilitator Instructions:**

- Print a copy of an ACP from the Children and Young Person's Advance Care Plan Collaborative: [Children and Young Person's Advance Care Plan Collaborative. Child and Young Person's Advance Care Plan ReSPECT Compatible](#)
- Encourage participants to work in pairs to complete the ACP either with reference to the care of Lila above, or with a particular local patient in mind, with anonymised information
- Review completed ACPs together as a group, and discuss challenging aspects

#### **Participant Instructions:**

- Complete an ACP with a particular patient in mind using anonymised information
- Utilise the below resource to assist in the process: [Child and Young Person's Advance Care Plan Collaborative. Guide to using the Child and Young Person's Advance Care Plan \(CYPACP\)](#)

## **The benefits of Paediatric Palliative Medicine (PPM)**

### **Activity: Journal Club**

#### **Objectives:**

4. Develop an understanding of the benefits of a specialised paediatric palliative care (SPCC) service and its current provision in the UK
5. Reflect on how SPCC could be further developed in the UK
6. Critically appraise a paper and discuss concepts of evidence based medicine

#### **Local Journal Club (45 minutes)**

#### **Instructions:**

- Discuss the following article: [Mitchell S, Morris A, Bennett K, Sajjid L, Dale J \(2017\). Specialist paediatric palliative care services: what are the benefits? \*Archives of Disease in Childhood\*. 102: 923-929](#)
- Nominate a trainee to lead the discussion and a consultant to facilitate
- All participants to read the article prior to the session
- Critically appraise the quality of the systematic review using the [Critical Appraisal Skills Programme \(CASP\) Systematic Review Checklist](#)
- Discuss the clinical implications of the paper
- Consider the requirements for developing a SPCC service using the following guide [World Health Organisation \(2018\). Integrating palliative care and symptom relief into paediatrics. A WHO guide for health care planners, implementers and managers.](#)

#### **Further Discussion:**

- Read the following paper: [Weaver MS, Heinze KE, Kelly KP, Wiener L, Casey RL, Bell CJ, Wolfe J, Garen AM, Watson A, Hinds PS. \(2015\). Palliative Care as a Standard of Care in Paediatric Oncology. \*Paediatric Blood Cancer\*. 62\(5\): S829-S833](#)
- Reflect on the specific benefits of palliative care within oncological services

## **Talking to children about death**

### **Activity: Group Discussion and Communication Scenario**

#### **Objectives:**

1. Understand children's developmental understanding of death and dying
2. Appreciate techniques for communicating difficult concepts with children
3. Manage the process of breaking bad news to a child and discussing death

#### **Group Discussion (30 minutes)**

##### **Facilitator Instructions:**

- Discuss the group's previous experience of communicating to children about dying
- Review the following resources together:
  - [Kuttner L \(2007\). Talking with Families when their Children are Dying. Medical Principles and Practice. 16:16–20](#)
  - [St Clare Hospice. A guide: how to talk to children about death and dying](#)
- Consider how to overcome some of the difficulties inherent in these conversations
- Ask if your departmental psychologist could assist with facilitation

#### **Role Play Activity (30 minutes)**

##### **Case**

15 year old Tyler has been receiving treatment for metastatic rhabdomyosarcoma for the last 9 months. His disease is resistant to treatment. His parents have been told his diagnosis is non-curative, and rapidly progressive. Tyler asks to speak to you.

##### **Candidate Instructions:**

- You are the Paediatric Registrar Oncall
- Talk to Tyler about his current clinical condition
- Answer any questions he may have about ongoing care and prognosis
- You have 10 minutes for the scenario

##### **Child Instructions:**

- You are aware that treatment is not working, and have heard hushed conversations between your parents and doctors
- Your mother is crying constantly and you know that the news is bad
- If not explicitly told- you ask if you are dying
- You are most afraid of being in pain when you die
- You do not want to be in hospital when you die, but want your parents to have help

##### **Facilitator Instructions:**

###### Assess

- Appropriate introduction and structured conversation
- Exploration of what the child already knows, and wants to know about the illness
- Is encouraging and supportive, provides appropriate but not false reassurance
- Addresses the child's concerns appropriately
- Summarises conversation and provides a mechanism for further conversation

**Discussion Points:**

- Communicating concepts of illness, death and dying to children can be incredibly challenging, but is an essential part of good palliative care
- It is important to first establish a basic relationship with the child, following this conversations can be tailored to the age and understanding of the child
- Babies and toddlers (0-3 years) while not understanding death, do feel loss and separation, and may reveal this in disrupted eating or sleeping patterns.
- Young children < 6 years understand something about death but cannot imagine forever. Reality and fantasy can be blurred, and emotions transient. It may be useful to evoke play to aid conversation (drawing, drama, stories led by the child).
- Children > 6 years have often begun to develop an adult understanding of death, acknowledging its permanence and inevitability; they may be fearful and curious.
- Adolescents have a similar understanding to adults and deserve to have a similar level of conversation about their own mortality and the process of dying.

## **The role of the Hospice**

### **Activity: Group Discussion**

#### **Objectives:**

1. Understand the different roles of the hospice in paediatric palliative care
2. Devise strategies to communicate these concepts to children and families
3. Recognise the impact of a palliative diagnosis on children, young people and their families

#### **Group Discussion (30 minutes)**

#### **Facilitator Instructions:**

- Work through the following tasks as a small group
- Discuss the group's previous experience of hospice care in paediatrics

#### **Watch the following short videos:**

- [Children's Hospices Across London. \(2020\). What is Hospice Care?](#)
- [Children's Hospice Week \(2020\). Royal Video Call.](#)
- [Each. Family Films.](#)

#### **Communicating concepts of hospice care to families:**

- Think about how to explain the role of the hospice to children and families
- Consider what challenges you might face and how to overcome these
- Role play the conversation in pairs and feedback useful tips
- Explore some of the difficulties of delivering hospice care during covid

#### **Discussion Points:**

- Children's hospices provide children, young people and their families with life-limiting conditions support in a myriad of ways
- This can include telephone advice, practical information, short respite care, access to specialist therapies, emergency care, end of life care and bereavement support.
- Care can be delivered in the families' own home or at the hospice
- Different families will have different requirements from hospice care, but every family who could benefit from hospice care, should be offered the chance

#### **Resources:**

[Together for Short Lives. \(2018\). family Factsheets: Children's Hospice Services](#)  
[St Clare Hospice. \(2016\). A little more about you Hospice.](#)  
[National Children's Bureau for Hospice UK. \(2019\). Children's palliative care and children's hospice provision in the UK.](#)