

We need to talk about Palliative Care

Royal College of Paediatrics & Child Health Scotland

1. What has been your experience in terms of access to palliative and end of life care?

- There are over 49,000 children and young people in the UK living with a life-limiting or life-threatening condition (Fraser et al. 2011 *Life-limiting and life-threatening conditions in children and young people in the United Kingdom; national and regional prevalence in relation to socioeconomic status and ethnicity: Final Report for Children's Hospice UK*, Leeds).
- The RCPCH Ethics and Law Advisory Committee recently revised and republished its guidance on: Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice:
http://adc.bmj.com/content/100/Suppl_2/s1.full.pdf+html
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- The Association for Paediatric Palliative Medicine (APPM) represents doctors working in paediatric palliative care across all care settings in the UK. The APPM therefore represents not only the small but growing number of specialist paediatric palliative care consultants who have completed GRID training in paediatric palliative medicine, but also paediatricians with an interest in paediatric palliative medicine and other doctors, particularly GPs with a specialist interest, many of whom are working in children's hospices.
<http://www.appm.org.uk/index.html>.

2. How could it be ensured that access to palliative and end of life care is equitable and available in all areas and for all types of terminal illnesses?

- Palliative care for children is different from adult palliative care and appropriate services for children and young people need to be available in all areas, in an appropriate location, whenever they need it, 24 hours a day, seven days a week. This must include specialist paediatric palliative medicine consultants and adequate specialist paediatric palliative care nursing provision so that every family of child with a life limiting condition has access to one. There needs to be consistent community children's nursing and support for children's hospices, both of which provide essential respite.

3. Can you identify any areas in terms of access to palliative and end of life care that should be focused on as priorities?

- Children's palliative care: The palliative and end of life care needs for children, young people and their families are significant and require particular attention. Specialist paediatric palliative medicine is

underprovided in the UK. These children have unique needs necessitating special consideration for care and service provision. Their care needs to reflect their age and developmental stage and embrace physical and emotional elements, as well as legal, ethical, and social factors relevant to their individual circumstances.

- Transition: The number of 16 to 19 year olds with life-limiting and life-threatening conditions has nearly doubled across the UK in the last decade (DHSSPS, 2014). Managing the transfer of their health and other care needs to adult services is challenging and adult services often struggle to provide appropriate services for young people with life-limiting conditions. Arrangements for transition should accord with best practice and be respectful—insofar as possible—of the wishes, preferences, beliefs and values of those concerned. Arrangements should accord with professional guidance and be subject to age-appropriate and/or age-determined legislation. For example, this might include provision of specialist paediatric palliative care nursing up to age 25.

4. When is the right time to begin discussing options for Palliative Care, who should be party to that discussion, who should initiate it and where should it take place?

- Palliative care can be introduced at any point throughout a child or young person's life; some may require palliative care from birth, others only as their condition deteriorates. In practice, palliative care should be offered from diagnosis of a life-limiting condition or recognition that curative treatment for a life-threatening condition is not an option. Each situation is different and care should be tailored to the child or young person.
- The introduction of palliative care should not be left until a decision is made to withdraw or withhold life-sustaining treatment. In making such decisions, families need as much information about the palliative care support available, and their options, as they do about the role of active interventions. Without this information, they cannot make an adequately informed decision to pursue or withhold/withdraw active interventions. Therefore, it is often helpful to involve a palliative care specialist early in the course of discussions.
- Discussions about palliative care should be conducted face to face, in privacy and families must be treated with respect, honesty and sensitivity. Emotional support should be available to families when significant news is being shared and, if possible, families should be together to receive the news.

5. What works well in discussing palliative and end of life care and how is good practise communicated? Where do the challenges remain?

- Discussions and decisions should be by clinical teams in partnership with the parents and child (if appropriate).

- The RCPCH believes that there should be a presumption that children and young people will be involved in decisions about treatment wherever possible and at a level that reflects their ability, understanding and experience. Although an assessment as to whether a child has legal capacity to make a decision about treatment is of the binary 'yes/no' type, appropriate involvement of children is practically important and ethically justifiable, irrespective of whether they have full capacity to make decisions for themselves. It is consistent with a rights respecting, non-discriminatory approach.
- Children's capacity to make decisions evolves over time and at different rates that broadly accord with their cognitive ability, developmental level and experience. Thus children who have had extensive experience of disease and its treatment, for example, repeated cycles of chemotherapy, organ transplantation, will have more informed views about continuing treatment than an adult facing such treatment for the first time. Equally, young children may have no experience of decision making and their value systems remain unformed.
- There are many ways of engaging children and involving them in decision making. These include (a) talking *with* them, (b) listening to them and responding to their concerns, (c) using appropriate techniques, for example, play to increase understanding and (d) acting in a way that demonstrates that account of their views has been taken.
- However, the vast majority of children and young people with life-limiting conditions are cognitively impaired and would not be able to engage in these discussions. Most end of life discussions are with parents.
- Because of the sensitive nature of the discussions, differences of opinion, often based on sincerely held beliefs and values, may occur between any of the parties. It is important to understand and attempt to resolve these differences using recognised support services for example, Patient Advice and Liaison Service (PALS), Clinical Ethics Services, chaplaincy. In cases where differences cannot be resolved by these means legal intervention may be necessary with courts as the ultimate arbiter of best interests.
- The parents may wish for limitation of treatments that healthcare teams regard as being in the child's best interests. This situation is rare, but if it arises the parents' understanding of the relevant facts and the reason for their judgment should be explored. If the benefits of continuing treatment are sufficiently small or uncertain, the parents' views about the best interests of the child should be given serious consideration. Where the benefit to the child is clear, the presumption should be to provide treatment to the child. An independent ethical review may be helpful, but it may be necessary to refer the case to the court for an independent judgment to resolve matters.
- The healthcare team may believe that limitation of treatment is in the child's best interests, but the parents do not agree and want treatment to continue. This is the more common situation. Parental wishes and

interests are important but not necessarily determinative; parents' wishes may be persuasive if the burdens to the child of further treatments are sufficiently small or uncertain.

- Parental interests may overlap with the interests of the child and are difficult to separate. An approach that considers family welfare rather than purely best interests of an individual child is a model that is used by the majority of paediatricians. Nevertheless, the interests of the child should remain the primary guiding factor in treatment decisions. Referral to social care and legal intervention should be considered when there is justifiable concern that parental decisions would pose a significant risk of serious harm to the child.
- 6. What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?**
- The anticipatory care plan or End of Life Care Plan (ECP) process provides children and families with a structured approach for discussing preferences around end of life care, and a record of what was discussed. To that extent, ECP fulfils the same function in children as discussions about wills, Advance Directives and Do Not Resuscitate orders in adults. The process includes dissemination of the ECP to professionals who need to know, including Ambulance, Police, paediatric, GP and emergency units (emergency department and children's assessment). To that extent, ECP also fulfils the same function in children as the palliative care register in adults.
- 7. How should information about Palliative Care be made available to patients and their family during any initial discussions and how easily available is this information?**
- Information should be provided for the child and the family in a form that is accessible and that they can understand. Their understanding of the information should be checked.
 - Written information should be used as a back up to face-to-face discussion; not as a substitute for personal communication.
 - Whilst there is a huge amount of general information available this can often be bewildering for families who need help in filtering it to what is relevant for them and in accessing it in a timely way. Providing details of support groups at the earliest possible stage can also be beneficial to families, for example, Contact a Family (www.cafamily.org.uk) and Together for Short Lives (<http://www.togetherforshortlives.org.uk/>)
- 8. What training and support is provided to Health and Care staff on discussing Palliative Care with patients and families and are there any areas for improvement?**

- Healthcare professionals need to be aware of the need for and means of accessing, specialist palliative care advice for children and young people with life limiting conditions.
- All healthcare professionals should have access to continuing education in communication, ethics and law for example, Mental Capacity Act and Equality Act. Ongoing delivery of training and the facility to reflect on challenging issues are key elements of good clinical practice.
- Multi-disciplinary and multi-professional learning opportunities should be developed which build on the inter-disciplinary ethos of palliative care.
- Members of healthcare teams will experience a wide range of emotions and failure to address them can lead to stress, sickness and lowered morale. Many team members may themselves need support.
- Families and other carers should be supported to develop and maintain the necessary knowledge and skills to provide care for children with palliative care needs. As more palliative and end of life care is provided in the community to children, it is crucial that families, carers and local communities, including volunteers, have the confidence and competence to take on these roles and responsibilities.
- Training in children's palliative care for undergraduates should be supported by Scottish Universities with the postgraduate curricula supported through RCPCH.

9. How do Health and Care organisations ensure that the discussions about palliative and end of life care are taking place at the right time?

- Health and Care organisations should ensure that all children with palliative care needs have their needs holistically assessed and regularly reviewed by a multidisciplinary team. Each child should have an identified keyworker who will plan and coordinate services for palliative care and support and ensure continuity of care for the child and their family.

10. What are the challenges in recording and documenting Palliative Care priorities and how well are those priorities communicated between different health and care providers?

- See response to question 6 on ECP.

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