

End of Life Care for Infants, Children and Young People: Planning and management

Review Questions

NICE Guideline

Methods, evidence and recommendations

12 May 2016

Pre consultation submission

*Commissioned by the National Institute for
Health and Care Excellence*

Disclaimer

Healthcare professionals are expected to take NICE clinical guidelines fully into account when exercising their clinical judgement. However, the guidance does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of each patient, in consultation with the patient and/or their guardian or carer.

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1 Review Questions

| Question Number | Review question |
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| 1 | What information and information type (written or verbal) is perceived as helpful and supportive by the family or carer before and after an infant, child or young person dies including managing practical arrangements, and care of the body? |
| 2 | What are the barriers and facilitators to effective communication between the child or young person, the family or carer and the healthcare professionals about the life limiting condition and likelihood of imminent death? |
| 3 | What are the barriers and facilitators to the infant, child or young person, the family or carer and the multidisciplinary team in being involved in decision making to inform the development, assessment and reviews of personalised, parallel and advanced care planning (including if appropriate decisions about continuing or stopping life-sustaining treatment and attempting cardiopulmonary resuscitation)? |
| 4 | What preferences do children and young people with a life-limiting condition and their family members or carers (as appropriate) have for place of care and for place of death, and what determines those preferences? |
| 5 | What aspects of communication and information provision facilitate or hinder discussions between children and young people with a life limiting illness and their family members or carers (as appropriate) with healthcare professionals to make decisions on organ or tissue donation? |
| 6 | <p>What services have to be in place to make rapid transfer available to take infants, children and young people with a life limiting illness to their preferred place of care in their last days of life as part of service delivery?</p> <p>Note. As an integrated part of the rapid transfer programme, particular consideration will be given to infants, children and young people who need compassionate extubation (including all life-sustaining treatment, e.g., non-invasive ventilation) in the preferred place (what services should be in place to facilitate)</p> |
| 7 | What is the effectiveness of 24/7 specialist telephone health care professional support (or parents/carers support), 24/7 community nursing support, and the combination of the two for the needs of infants, children and young people with life-limiting conditions, and for the needs of their family members and carers (as appropriate) during this time and after death as part of service delivery? |
| 8 | What is the clinical and cost effectiveness of a defined multi-disciplinary team (MDT) of a particular composition compared with one of a different composition and compared with care without a defined MDT? |
| 9 | What is the clinical and cost-effectiveness of a home-based programme of care compared with care in other settings? |
| 10 | Are psychological interventions effective for infants, children and young people with life-limiting conditions and what factors influence the attitudes of children and young people and the family's involvement and decisions about choices of |

| Question Number | Review question |
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| | those interventions? |
| 11 | Are psychological interventions (including short term bereavement therapies) effective for family members and carers of infants, children and young people and what factors influences their attitudes about those interventions before and after the death of an infant, child or young person with a life-limiting condition? |
| 12 | What factors of social and practical support (including care of the body) are effective in end of life care of infants, children and young people with life-limiting conditions and their family members or carers (as appropriate) and what influences attitudes about these before and after death? |
| 13 | What factors of spiritual or religious support (including care of the body) are effective in end of life care of infants, children and young people with life-limiting conditions and their family members or carers (as appropriate) and what influences attitudes about these before and after death? |
| 14 | What pharmacological and non-pharmacological (excluding psychological) interventions are effective for the management of pain in of infants, children and young people with life-limiting conditions? |
| 15 | What pharmacological and non-pharmacological (excluding psychological) interventions are effective for the management of agitation in of infants, children and young people with life-limiting conditions? |
| 16 | What pharmacological and non-pharmacological (excluding psychological) interventions are effective for the management of respiratory distress in of infants, children and young people with life-limiting conditions? |
| 17 | What pharmacological and non-pharmacological (excluding psychological) interventions are effective for the management of seizures in of infants, children and young people with life-limiting conditions? |
| 18 | What is the effectiveness of medically assisted hydration in infants, children and young people during end of life care? |
| 19 | What is the effectiveness of medically assisted nutrition in infants, children and young people during end of life care? |
| 20 | What signs and symptoms, individually or in combination, help to recognise the infants, children or young people are likely to be in the last days of life and which of them are considered most informative by healthcare professionals? |