

Paediatric palliative care

Angela Thompson

Abstract

Children with palliative care needs are increasing in prevalence and complexity of need. 49,000 children (under 19 years) were estimated to be living in the UK in 2012 with a life limiting/life threatening condition that might require palliative care.

Palliative care requires a total and active approach, with transparent, communicated, agreed provision of appropriate and proportionate care. Planning improves care, supported by documentation of plans. Advance planning enables management of both reversible and chronic aspects of the condition, as well as utilising parallel planning when end of life approaches.

Challenges in palliative care include the commissioning of sustainable services across organisations to deliver, often over years, but sometimes briefly and rapidly, 24/7 access to skilled palliative care, including hands on care at the end of life. Care is integrally intertwined with other clinical, social, education and voluntary services to ensure that families receive the spectrum of care required throughout their journey.

Keywords advance care; best interest; end of life; life limiting; palliative; parallel planning; planning; sustainable

Background

Paediatric palliative care is an often under-recognised care need, and yet its need is increasing. The national prevalence of life limiting conditions in England had doubled from 16 per 10,000 in 2007 to 32 per 10,000 (aged 0–19 years) in England in 2009/10. Over 49,000 children (under 19 years old) were estimated to be living in the UK in 2012 with a life limiting or life threatening condition that might require palliative care (Fraser, 2012). Need has increased not only in numbers but also in the complexity of the conditions and the technology which supports babies, children and young people ('children') with life limiting/life threatening conditions as they live, and are cared for, at the advancing edge of new developments in medical, surgical and technological care.

Paediatric palliative care is defined as 'an **active and total** approach to care, from the time of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child and young person and support for the family. It includes the management of symptoms, provisions of short breaks and care through death and bereavement.' (Together for Short Lives, TfSL).

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Life Limiting/Threatening Conditions, courtesy of Together for Short Lives

The four TfSL categories encompassing the spectrum of conditions which may lead to palliative care needs, give insight into who might come under the umbrella of palliative care

Group 1

Life threatening conditions for which curative treatment may be feasible but can fail. Examples include cancer, or irreversible organ failures such as heart, liver or kidney.

Group 2

Conditions where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities, but where premature death is still possible or inevitable. Examples include cystic fibrosis, Duchenne muscular dystrophy.

Group 3

Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. Examples include Batten disease, mucopolysaccharidoses.

Group 4

Includes conditions such as severe neurological disability, where the underlying condition may be static but which may cause weakness and susceptibility to complications leading to premature death. Examples include severe multiple disabilities such as severe cerebral palsy or post severe head injury.

Box 1

Children with palliative care needs have an underlying, often complex, life limiting or life threatening condition. Their needs are considered palliative because the family lives with the threat of death, even though the child may ultimately survive with no, or varying degrees of morbidity. **A life limiting condition (LLC)** is one where there is no reasonable hope of cure and from which children will die. **A life threatening condition (LTC)**, however, is one for which curative treatment may be feasible but may fail (Box 1).

Whilst palliative care covers the whole range of care needs from diagnosis/recognition through to bereavement, end of life care (EOLC) focuses specifically upon the phase where death is anticipated, where disease progression can neither be expected to be halted nor reversed. Even in such circumstances, however, it is not unknown for a child to move back and forth from apparent EOLC into palliative care again before facing their final EOLC phase.

Uncertainty in prognosis and parallel planning

This uncertainty in prognosis has led to deliberation over how best to recognise EOLC and to manage doubt around such times. Prior to this stage, the child may have experienced recurrent episodes of acute illness, gradually progressing to a more rapid demise from apparently less severe intercurrent illnesses, with a

subsequent slower recovery to a poorer health state. Parents often report a change; *'He didn't need to be admitted when he caught a cold last year, he just had antibiotics at home; but now he's needing intravenous antibiotics almost as soon as the illness begins, and it's a slow job to get back to where he was before. In fact he never seems to get back to being as good as he was'*. They may report a new gathering of symptoms from multiple systems, impacting adversely upon each other. It is then that the approach of **parallel planning** can be of help, beginning to redefine and shift aims, enabling services to be re-planned and re-directed as families retain the ability to hope for the future, whilst also recognising the reality that things may not now go as well as they had hoped, so 'hoping for the best whilst planning for the worst'. It is at this stage that families often describe their journey. Sometimes they describe having felt too exhausted to climb a mountain that seemed to loom ahead; where the ethical issues and gathering symptoms seemed too overwhelming to climb and negotiate safely. This stage often becomes eventually replaced with relief at retuning back to the security of the 'valley floor' below, once the acute, intertwined symptoms and ethical issues are managed. Yet, often, it is then that the parents realise that they are now in a different place within the valley floor; rather than walking as previously on the firm path by the side of the river, they now step across slippery stepping stones. Life has become fragile and health deteriorations may no longer be reversible nor progression halted. There has been a turn in the road, to end of life care. But where the end of that road is, and what other turns and corners are still to be negotiated, often remains unknown.

Prognostic factors

Prognostic factors, if clear, would help in this deliberation. As in adult palliative care, prognostic factors in paediatric EOLC are more readily identified in the final days than in the earlier weeks and months. However, in general, the significance is in the shift of the impact of the symptoms which become more resistant to treatment and often tend to present as concurrent comorbidities rather than intermittent individual symptoms, as the EOLC phase progresses. The approach utilised in adult palliative medicine, 'would I be surprised if this individual died in the next 12/6 months?' is an equally helpful trigger in paediatrics to discussion and provision for EOLC.

Planning ahead

Planning ahead is a natural part of the care any doctor undertakes for any patient; for the anticipated management of reversible aspects of their condition and for more chronic aspects and complications less amenable to intervention. Planning ahead in paediatric palliative care encompasses this too, from the time of diagnosis, sometimes over many years, sometimes briefly and rapidly in aggressive deteriorations. It builds discussions step by step around managing changes that cannot be reversed but may be anticipated. Planning for potentially reversible intercurrent events is essential, based upon what is known about the potential complications of the child's underlying condition and previous events in the child. Listening and managing these effectively builds trust and respect between families and professionals for the future. What essential information does the ambulance crew

or junior doctor need to know to help manage them? What crises might be expected? What decisions about future care have already been reached? Who can be contacted 24/7 about this child?

Besides planning for such medical aspects of the condition and their interventions, it is also important to plan for what matters to the child and family in relation to the condition and its impact upon living with (and dying from) it – how to normalise life, provide positive opportunities and support for their unique family. 'What matters to you, if I am to help get this right for you?' Health, education, social and voluntary care all have a role to be respected. Palliative care is **everyone's** responsibility with specialist services working alongside generic and universal, if the families are to receive holistic care throughout their journey.

As the condition approaches EOLC, planning for the time around death becomes increasingly important. Edwards describes that families enabled over time to articulate their goals for their children in scenarios of relative health and worsening illness, increasingly recognise that these wane and wax respectively, enabling emphasis to gradually shift towards planning around EOLC. Where conditions progress rapidly, the same applies; it remains paramount to know what matters to the family alongside how to implement best practice care, whilst supporting families in ways specific to their needs.

Conversations therefore involve planning for life and when appropriate, planning for EOLC. Families' willingness to have such discussions deserves that they are well recorded and updated timely, communicated appropriately, according to best practice, with families consent and stored securely. Identifiable standardised documents (often colour coded), often called Advance Care Plans (ACPs), for recording such conversations, can be helpful. They enable identifiable documentation of previous discussions, summarised, in a clear manner that can facilitate future care in all care settings the child may use, rather than allowing information to be potentially 'wasted' where documented in previous letters or within reams of records. Such discussions involve relevant members of the child's wider clinical team along with the family, in an open and transparent manner. The lead clinician takes responsibility for documentation and updates. Decisions need to be in keeping with Royal College of Paediatrics and Child Health (RCPCH) ethical guidelines and in the child's best interest. Documentation of decisions should be regarded simply as a summary of discussions at that particular time, not as a legal document and may be changed if circumstances or opinions/wishes change, **whilst ensuring that the child and their best interest remain central to the decisions reached and care provided**. Many children with ACPs have plans for active resuscitation. ACPs in Paediatrics are primarily active plans for the child's future total care in life and when appropriate, may contain plans relating to end of life. Advance Care Plans in Paediatrics are not the same as Advance Directives in adults and this distinction must be kept clear.

Benefits of planning ahead

Planning ahead may have a range of favourable consequences. Dussel looked beyond the preferred place of death outcome, for children with cancer. Where families had planned location of

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