

Finding Solutions to complex issues
The All-Party-Parliamentary Group: Dying Well
Co-chair Baroness Finlay
Supported by: The Association for Paediatric Palliative
Medicine
Tuesday 23rd January 2024

Key Statements

1. We need to raise awareness in the public domain regarding the complexity of medical decision making and the moral distress regarding continual interventions to a child when it is not in their best interests for all those involved including parents and health care professionals.
2. We recognise that as experts we should be stepping forward, as we did at the APPG, offering public advocacy around this issue to inform and engage with the public and policy makers- ultimately ensuring that the child remains the focus and at the heart of the discussion, the decisions and care provided.
3. We recognise that this issue remains unabated and unaddressed in the face of increasing prevalence of children with life-limiting conditions.
4. We recognise the need to improve support for parents and professionals when navigating these complex decisions on behalf of the child.

Background

Children and young people with life-limiting conditions, their families and those professionals working with them are facing increasingly complex, and inherently distressing decisions when a child's condition changes, and they are facing the end of their life. Over the past several years legal cases on behalf of the child or young person regarding decisions related to medical interventions have been reported in the media and debated in the public domain. Often these cases focus on decisions to cease ventilation or other life-prolonging treatment or interventions.

Professionals from around the country were invited to share their experiences at the APPG for Dying Well. All those in attendance were offered the opportunity to share their perspective on these complex issues and discuss some of the challenges faced. The focus of the meeting was to consider and propose some solutions to this emotive and complex area of child health. The professionals attending included doctors, nurses, psychologists and lawyers from around the country working in hospital or community-based teams, specialising in intensive care, palliative care, general paediatrics and respiratory medicine.

Summary and extracts

Colleagues shared lived experiences of caring for this very special group of babies, children and young people and their upmost concern for the child's wellbeing and their role in advocating for them without bias. The summary below captures some of the prepared speeches given during the APPG.

Definitions

Children with life-limiting conditions are those where management options may be available but where death in childhood or early adulthood is sadly inevitable or highly probable. Whereas children with life-threatening conditions may have curative treatments which are possible but there is still a significant risk of death.

Data

In England¹	2001 – 2002	2017 -2018	Predicted 2030
Number of children with life-limiting or life-threatening conditions	33,000	86,000	
The prevalence of children with life-limiting conditions aged 0 -19 years	26.7 per 10,000	66.4 per 10,000	84 per 10,000
Number of children with life-limiting conditions with prolonged hospital stays (>28days)	2482	3538	

The prevalence is highest in children under 1 year of age – affecting over 226 children per 10,000 in 2017/18.

The reason for a rise in the number of children with life-limiting and life-threatening conditions is multifactorial. The most significant contributors maybe the increasing number of medical interventions that can be used to prolong life when cure is not possible, and the advances in neonatal medicine. Despite more babies and children surviving from younger ages for longer periods of time, sadly the number of life-limiting conditions where cures have been found remain low.

There has also been an increase in prolonged hospital admissions (>28days). With the activity in children’s intensive care units also significantly increasing in the last 10 years. The increase in intensive care bed stays has not been matched with an equitable rise in admissions. This means that the same children are requiring more frequent and prolonged admissions to the intensive care units. At any given time, 50-60% of the children receiving care on a paediatric intensive care unit will have an underlying life-limiting condition.

Medical Interventions

Medical interventions are becoming increasingly technical and complex. For example, to manage artificial nutrition and hydration, some children require surgically placed feeding tubes into their gut and in some cases directly into their bloodstream. These methods of supported nutrition require general anaesthetics and hospital admissions. Whilst this may support nutrition, it also brings significant longer-term complications and side effects that also need managing.

Some children with breathing difficulties require respiratory support for some or all of their day and night. This support can range from the use of oxygen, through to ventilators and tracheostomies (hole through the neck and into the windpipe). These interventions are often uncomfortable and are not without risk. Parents may find themselves running a small intensive care at home, for which they require training and may need to give up work to deliver this care. Recruitment and training of specialist nurses, carers and other health care professionals who work within the home, school, and community settings in order to support the child’s care safely and sustainably is required. Children often require prolonged stays in hospital until all this support and training is in place.

The cost to families

In addition to the care that is needed, there is also a plethora of equipment required – including but not exhaustive of syringes, nappies and pads for children who are doubly incontinent, feeding pumps, suction machines, nebulisers, ventilators, wheelchairs, hoists, hospital beds, adapted baths, safe storage for artificial feeds and medications. Homes begin to mimic intensive care units. This requires space (for equipment and staff) and electricity – highlighted more acutely within the context of the cost of living crisis. The ask on families cannot be underestimated – with reported higher rates of marital breakdown, poor mental health, financial struggles and unemployment^{2,3}. The impact extends beyond the child but to their parents, siblings, and extended family members.

Workforce

The workforce has not grown to meet the increasing demand in care and with a chronic lack of investment in paediatric palliative care across the board. It has sent a message that the care of a dying child is not a priority within today's society. There is a lack of funding for both statutory and non-statutory services (such as hospices) resulting in a postcode lottery of care support and packages for families who are often being asked to take on increasing levels of responsibility and burdens of complex care delivery.

Medical decision making

Children with life-limiting conditions are supported by multiple teams including acute subspecialty services within hospitals, local paediatric services, intensive care, and palliative care services. The role of these professionals is to support children and their families in all aspects of their care, to be a source of knowledge, regarding diagnosis, treatment options and prognosis as well as to advocate for children.

It is vital to be able to differentiate between what is feasible and what is likely to bring meaningful benefit to the child. There may always be something else that could be tried: a different ventilator setting, a different drug, a different feed regime or another doctor to ask. How do we work out what we should do and not just what we could do?

Decision making for children with life-limiting conditions can be challenging – particularly on intensive care units when emotions can run high as children are very sick and vulnerable. There can often be prognostic uncertainty. Families and professionals embark on a journey together with an ever-changing landscape requiring repeated discussions.

Conflict

In recent years there has been a rise in high profile cases where the parents and carers of children with conditions that are life-limiting have come into conflict with the health care professionals responsible for caring for their children. Whilst at any given time, there are 10s of cases like this on the Paediatric Intensive Care Units across the UK, only a small handful make it into the public arena. The families involved have often been tasked with decision making that is enormously challenging for any family whilst facing immense grief for the child that will sadly die.

In the majority of cases, conflict can be resolved. In some situations, the support of mediation, advocacy services or the advice of clinical ethics advisory services is also utilized. Whilst these can be very valuable tools, in some cases they may not be helpful and in the worst-case scenarios perceived by parents as an added burden in a world they are already finding traumatising. In some cases, a legal process is required, and for some families this approach has been helpful. The recent changes to legal aid funding for families now enables some very low-income families to pursue a legal process without resorting to public engagement and social media events to fund raise for their legal fees.

Media

High-profile medical cases have often attracted not only conventional media attention but a rise in social media too. Dying is rarely talked about, let alone a child dying. We live in a society where death is seen as failing, where people constantly search for more and more possible options to stave off death, however distressing and unlikely they are to help. There is no denying that dying in childhood is the wrong order of things. People expect to bury their parents but not their children. However tragically, children are not immune from dying. It is not common, but it is not as rare as people think. When these high-profile cases flood the media in a sensational way, often only one side of the story is shared. It is highly emotive. No one can help but feel desperately for the loving, hurting, grieving parents, their families, and friends. The complexity in the decision making can be reflected sometimes when parents, between themselves, do not agree on what they believe is best or right for their child. Both healthcare professionals and parents alike seek to advocate in the child's best interest. Healthcare professionals are bound by confidentiality and maintain their professional silence. They are not able

share publicly, why, and how they believe a child is suffering. They may feel that they are not prolonging a child's life but prolonging a child's death and suffering.

The vilification of some healthcare professionals in the media has led to episodes of reprisals and trolling resulting in highly trained and skilled professionals leaving their roles or requiring prolonged periods away from frontline clinical care. This has significantly impacted on the care provided to the individual child, to other patients and the services seeking to continue to provide highly quality care.

Paediatric Palliative care

Palliative care has often been portrayed as the final step for a child and can be perceived as "giving up". The reality however is that Palliative care for children and young people with life-limiting conditions is an active and total approach to care. With teams looking after babies, children and young people, from the point of diagnosis or recognition of illness, throughout the child's life and through to their death. This differs from adult palliative care which in the main focuses on a patient's last 12 months of life. Palliative care support is in collaboration with other healthcare professional teams with a shared goal to improve or maintain the child's quality of life. The focus of all teams is to keep a child well, comfortable and dignified as well as supporting their families through the child's illness and death.

Finding solutions

As healthcare professionals, we want to move forward collaboratively to find solutions to how we approach, consider, and manage these complex, intricate discussions regarding care decisions for very unwell children when communication between families and professionals start to falter.

We need to recognise and intervene early when this occurs. The use of a toolkit type approach, offering a choice in how to support complex discussions is recommended and could include the offer of a second opinion, the use of advocacy, mediation and a clinical ethics committee. None of these options should be mandatory since where some may find benefit, providing independent scrutiny and focused consideration, others may consider some options to be pedantry and inflammatory. These optional options should be freely available to all families and professionals and utilised according to the individual needs of the child and their family. We acknowledge the need on occasion for the use of a legal process which has proven beneficial and supportive for some families.

Understanding potential triggers to conflict and disagreement may offer opportunities to reduce the risk of adversarial encounters and discussions. Ensuring appropriate and adequate support for children and families is imperative. Systems providing support, across health and social care, to children with high care burdens, are usually heaving and over-whelmed, leading to intermittent, unreliable, or absent provision of support. The support is often limited by the lack of a skilled workforce and consistent, sustainable funding. This results in parents coming to these complex, -life and death-, discussions already with preloaded narratives of being let down- often repeatedly, exhausted and mistrusting of the systems which were meant to support their child, them as a family and the healthcare professionals working in them.

Further Questions to ask to policymakers and politicians:

The development of legal aid funding for families to navigate the complex area of legal decision making regarding medical interventions related to their child is welcomed. Can his majesty's government confirm that legal aid in cases where medical treatment might be withheld or withdrawn is no longer means tested?

The benefit of paediatric palliative care in supporting children with life-limiting conditions and their families, when faced with complex decisions related to withdrawal or limiting medical interventions is well known. What funding and assurances are in place to ensure sustainable equitable paediatric palliative care services are available to all children across the UK?

Recognising the continued increase in numbers of children with life-limiting conditions in the UK, what does the government believe is the solution to address the widening gap of support including funding and a skilled workforce to meet the needs of these children and their families? Now and for the future?

Reference

1. Fraser L, Gibson-Smith D, Jarvis S, Norman P, Parslow R. Estimating the current and future prevalence of life-limiting conditions in children in England. *Palliative Medicine* 2021; 35(9):1641-51.
2. Zhao X, Hu H, Zhou Y, Bai Y. What are the long-term effects of child loss on parental health? Social integration as mediator. *Comprehensive Psychiatry*; 2020; 100:152182.
3. Song J, Floyd F, Seltzer M, Greenberg J, Hong J. Long-term effects of child death on parents' health related quality of life: A Dyadic analysis. *Fam Relat.* 2011; 59(3):269-282.

AGENDA

- 1. Setting the context: Children with life-limiting conditions and their families facing the unthinkable**
Dr Jo Laddie, Consultant in Paediatric Palliative Medicine, Deputy Clinical Director, Chair of GSTT Clinical Ethics Advisory Group, Evelina Children's Hospital
- 2. Clinical humility and parental engagement**
Dr Finella Craig, Consultant in Paediatric Palliative Medicine, Great Ormond Street Hospital for Children NHS Foundation Trust
- 3. Complexity and medical intervention**
Dr Will Tremlett, Consultant in PICU and KIDS/NTS, Birmingham Women's and Children's NHS Foundation Trust.
- 4. Moral distress and harm**
Dr Clare Chamberlain-Parr, Clinical Psychologist, Alder Hey Children's NHS Foundation Trust
- 5. Involving the public**
Dr Michelle Hills, Consultant in Paediatric Palliative Medicine, Leeds Teaching Hospital NHS Trust and Martin House. Chair of CSAC for Paediatric Palliative Medicine, Royal College of Paediatrics and Child Health
- 6. The role of legal engagement**
Sophie Pownall, Trust Solicitor and Head of Legal for Great Ormond Street Hospital
- 7. Recommendations: Finding solutions**
Dr Anna-Karenia Anderson, Consultant in Paediatric Palliative Medicine, Royal Marsden Hospital and Shooting Star Children's Hospice. Chair of Association for Paediatric Palliative Medicine

ASSOCIATION FOR PAEDIATRIC PALLIATIVE MEDICINE

we are a non-profit making organisation
and we aim to

- promote the practice of paediatric palliative medicine
- promote and develop the community of paediatric palliative care through education, networking and communication
- develop standards and guidelines of good practice in the field of paediatric palliative medicine
- support all those working with children with palliative care needs and their families

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