Knowledge, understanding and learning to improve young lives

Infants, children, and young people with life-limiting conditions

Learning from child death reviews on palliative and end of life care provision

National Child Mortality Database
Programme Thematic Report

Data from April 2019 to March 2022

Published July 2025

Painting by Emily Tammam, bereaved parent of Neve

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Information on data tables, methodology, limitations, and references, is available in the Supporting Material and Data Tables.

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Cover image painted by Emily Tammam, on Arches Aquarelle 300g cold pressed watercolour paper. Painted with watercolour paints from The Stoneground Paint Company.

The hands represent the relationships and connections at the heart of birth, life, and death. These include all the connections between and among health professionals, families and children. As a bereaved parent, I remember the soft feel of my daughter Neve's hand, from that of a tiny infant through to her bedside, in hospital, in our hospice and ultimately, at home, just before and just after her death.

The patches of light on the hands are rays of sunlight and they represent our experience of palliative care; it brought glimmers of light, when everything felt heavy and overcast. Sometimes palliative care felt like an umbrella, shielding us from the rain and other times, like sunshine, when it was otherwise dark. We could not stop Neve dying but as a team, we could ease some of her suffering. In the time when we knew and understood that our daughter would die, it was palliative care that brought us this warmth, connection, and support.

Contents

Introduction

The terms ‘child’ or ‘children or young people’ are used interchangeably in this report to represent all children aged 0–17 years inclusive. The term ‘infant’ refers to children aged under 1 year.

Every child who dies is a precious individual and their death represents a devastating loss for parents, siblings, grandparents, carers, guardians, extended family, and friends. With all child deaths there is a strong need to understand what happened, and why. We must ensure that anything that can be learned to improve services is identified and acted upon.

This report is about children who were very unwell, had congenital anomalies, cancer, or other conditions that meant that they may have been expected to die earlier than usual. These conditions are also known as life-limiting conditions. Life-limiting conditions are defined as those for which there is no reasonable hope of cure and from which children may die[1]. Some conditions cause progressive deterioration, meaning that the child becomes increasingly dependent on parents and carers.

Previous studies have shown that the number of children living with life-limiting and life-threatening conditions is increasing[2]. There is also evidence that children with these conditions are living longer. This means that more children and young people will require support from palliative care and end of life services. We need to understand what is currently working and where improvements are needed. Palliative care for children with life-limiting or life-threatening conditions is an active and total approach to care. This care can last from the point of diagnosis all the way through the child’s life and their death[1]. It embraces physical, emotional, social, and spiritual elements, and focuses on enhancing the quality of life for the child and support for the family. This care includes the management of distressing symptoms, provision of short respite breaks for children and families, and care through death and bereavement.

This report analyses data from the child death reviews in England of children who have died with, but not necessarily of, a life-limiting condition, in the period between 1 April 2019 and 31 March 2022, as recorded on the National Child Mortality Database (NCMD). It presents the characteristics of the children who have died and an analysis of the national themes and learning on palliative care services, as recorded in the completed reviews by the Child Death Overview Panels (CDOPs). Information on how children with a life-limiting condition were identified, and the conditions included, is available in the Supporting Material.

The period was restricted to deaths that occurred between 1 April 2019 – 31 March 2022 to ensure that most (96%) of the deaths during this period had been reviewed by CDOP. This ensured the most complete information was reported. In addition, Hospital Episode Statistics (HES) data had only been provided for deaths up to 31 March 2022 and data linkage was not possible for deaths that occurred after this date.

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[1] Together for Short Lives (2018)
[2] Together for Short Lives (2020)

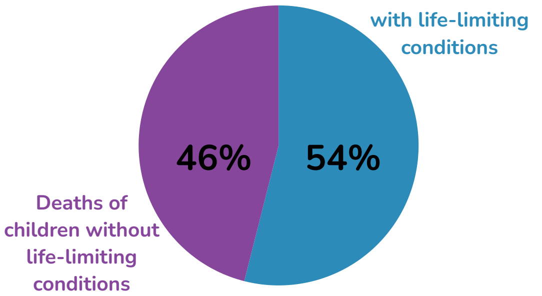
Deaths of infants, children and young people with life-limiting conditions and palliative and end of life care analysis.

NCMD
National Child Mortality Database

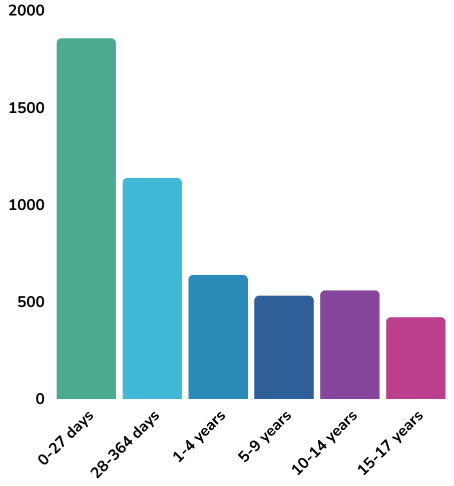
CDOP reviews highlight improvements needed in:

- Appropriate parallel planning and timely engagement with palliative care
- Documented and accessible advance care plans
- Appropriateness, timeliness and availability of prescribed medications
- Leading and coordinating care by a named medical specialist
- Commissioning and funding of palliative care services
- Bereavement support and allocation of a key worker

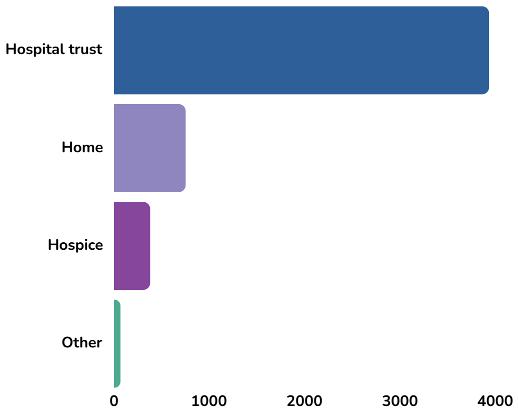
54% of all child (0-17 years) deaths between 1 April 2019 and 31 March 2022, were of children who had a life-limiting condition (LLC)



58% of deaths of children with a LLC were aged under 1 year



77% of children with a LLC died in hospital



Full findings from the report, including recommendations, can be found at ncmd.info/publications/LLC

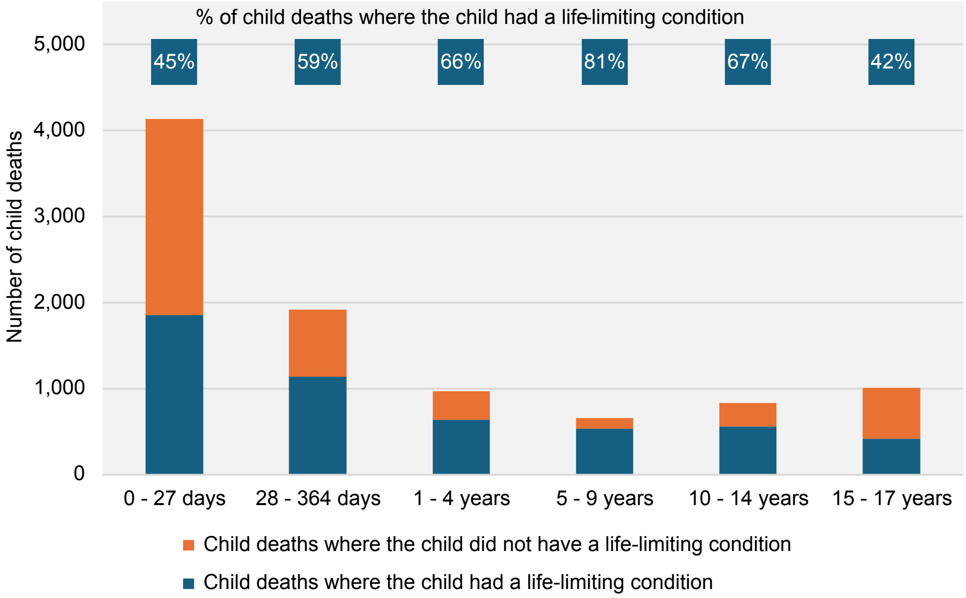
1. Characteristics of children who die with a life-limiting condition

This section reports the number and characteristics of child deaths between 1 April 2019 and 31 March 2022 where the child had a life-limiting condition.

Of all child deaths that occurred between 1 April 2019 and 31 March 2022 in England (n=9517), 54% (n=5134) were of children who had a life-limiting condition. This is similar to the proportion in Wales reported previously (53%)[3].

This proportion varied by age, with the highest proportion in those aged 5-9 years (81%) and the lowest in those aged 15-17 years (42%) (Figure 1). However, the highest number of deaths of children with a life-limiting condition was in the neonatal (0–27 days) age group (n=1855), followed by those aged 28–364 days (n=1136). These two age groups (infant deaths) represented 58% of deaths of children with a life-limiting condition. Where it was known, 59% (n=1733/2952) of infants (children aged under 1 year) who died with a life-limiting condition were born prematurely (before 37 weeks' gestation) (Figure 6).

Figure 1: Number of child deaths between 1 April 2019 and 31 March 2022 where the child did or did not have a life-limiting condition, by age at death



Overall, there were higher numbers of deaths of children with and without a life-limiting condition in the most deprived neighbourhoods in comparison to the least deprived neighbourhoods (Figure 2). Previous research has shown there is an association between the risk of child death and the level of deprivation for most causes of death[4].

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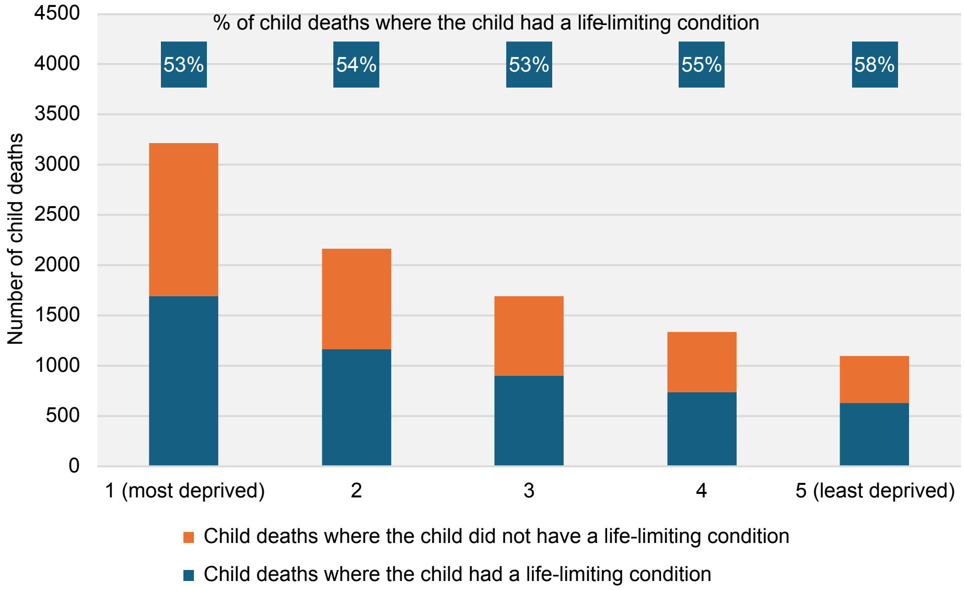
[3] University of York (2023)

[4] National Child Mortality Database (2021)

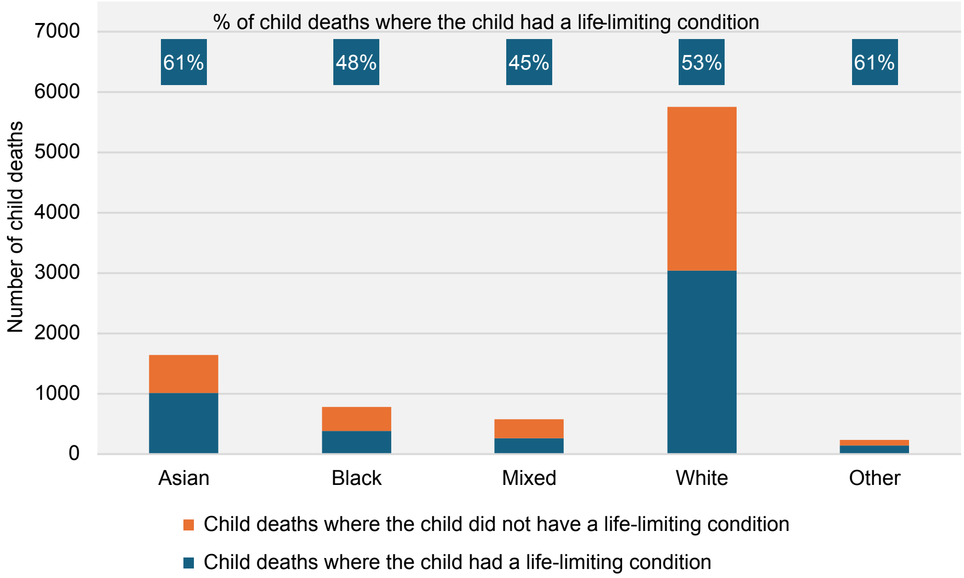
Figure 2: Number of child deaths between 1 April 2019 and 31 March 2022 where the child did or did not have a life-limiting condition, by social deprivation



For children with a life-limiting condition, 3045 (63%) were of white ethnicity, 1011 (21%) of Asian ethnicity, 379 (8%) of black ethnicity, 263 (5%) of mixed ethnicity, and 143 (3%) of other ethnicity.

Of all deaths of children from an Asian or other ethnic backgrounds, 61% (Asian: n=1011/1645, Other: n=143/234) had a life-limiting condition. This was higher than the proportion of deaths where the child had a life-limiting condition across white (53%, n=3045/5754), black (48%, n=379/782), or mixed (45%, n=263/582) ethnic backgrounds (Figure 3).

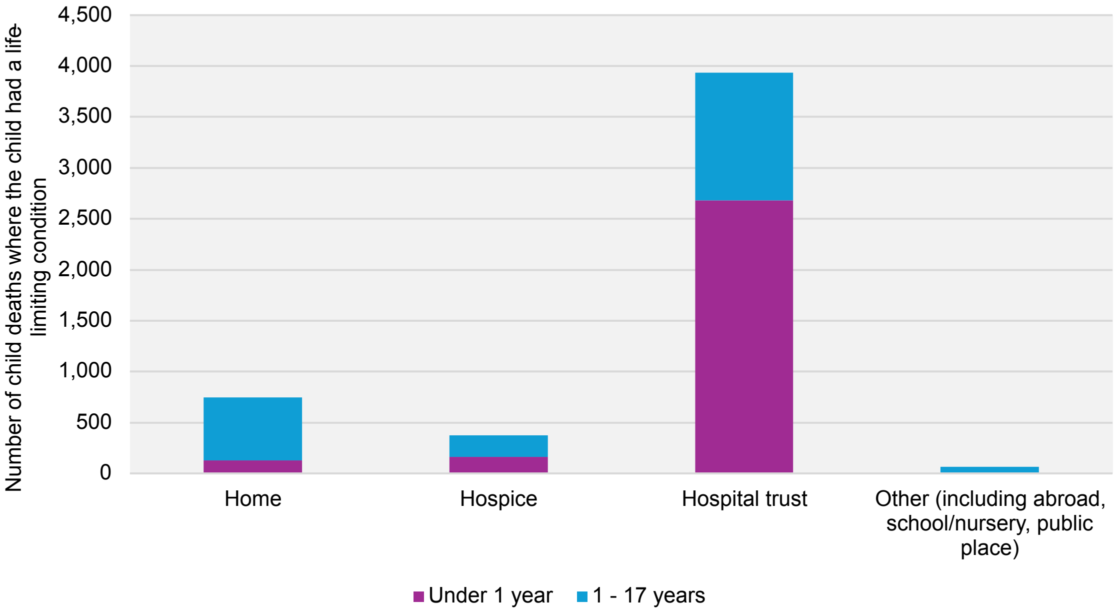
Figure 3: Number of child deaths between 1 April 2019 and 31 March 2022 where the child did or did not have a life-limiting condition, by ethnicity



Of children who died with a life-limiting condition (n=5134), 77% (n=3935) died in a hospital trust, 15% (n=749) died at home, and 7% (n=376) died in a hospice (Figure 4). These proportions are similar to those reported previously and that have been reported for nearly 20 years[5]. For deaths of children aged under 1 year with a life-limiting condition (n=2990), where it was known, 90% (n=2684) died in a hospital trust and 5% (n=162) died in a hospice. This is consistent with previous research from Wales[3] and Scotland[6]. For children aged 1-17 years with a life-limiting condition (n=2134), 59% (n=1251) died in a hospital trust, 29% (n=617) died at home, and 10% (n=214) died in a hospice.

Whilst similar trends have been shown for many years, it is important to note that the time period in this report includes deaths that occurred during the COVID-19 pandemic. The restrictions put into place during the pandemic may have impacted the place of death.

Figure 4: Number of child deaths between 1 April 2019 and 31 March 2022 where the child had a life-limiting condition, by place of death



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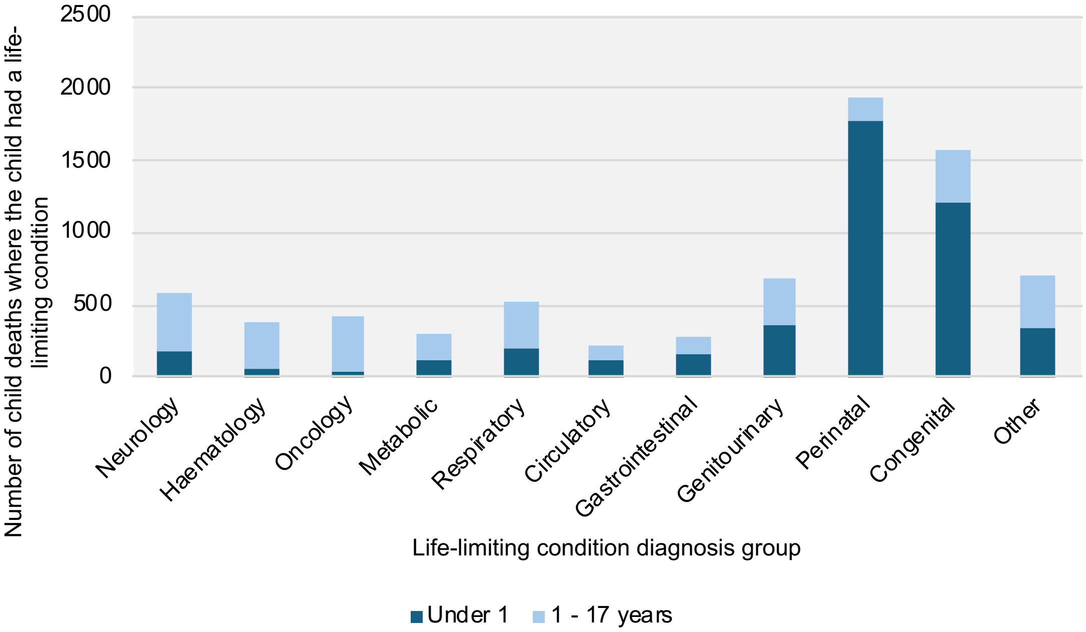
[5] Gibson-Smith et al (2021)
[6] University of York (2015)

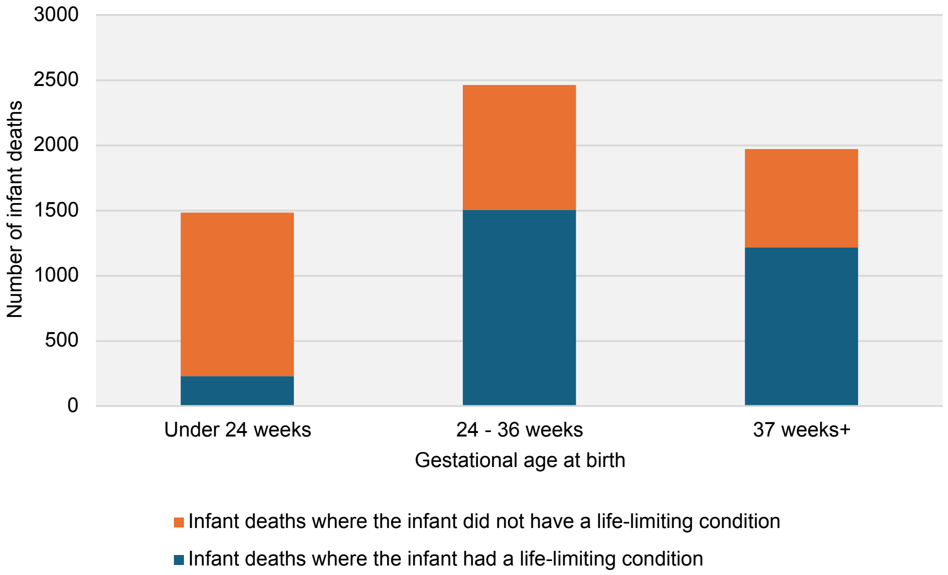
The highest number of deaths occurred in children with an underlying perinatal (39%, n=1994) or congenital life-limiting diagnosis (35%, n=1795) (Figure 5). Gestational age distribution for infant deaths is presented in Figure 6. A further breakdown of data by diagnosis and age group is available in Table 6.

Figure 5: Number of child deaths between 1 April 2019 and 31 March 2022 where the child had a life-limiting condition, by life-limiting condition diagnosis group



N.B. Categories are non-exclusive: a death may be recorded under multiple categories. Life-limiting condition diagnosis group was derived from ICD-10 diagnoses recorded in hospital episode statistics data, a list for each group is available in the Supporting Material.

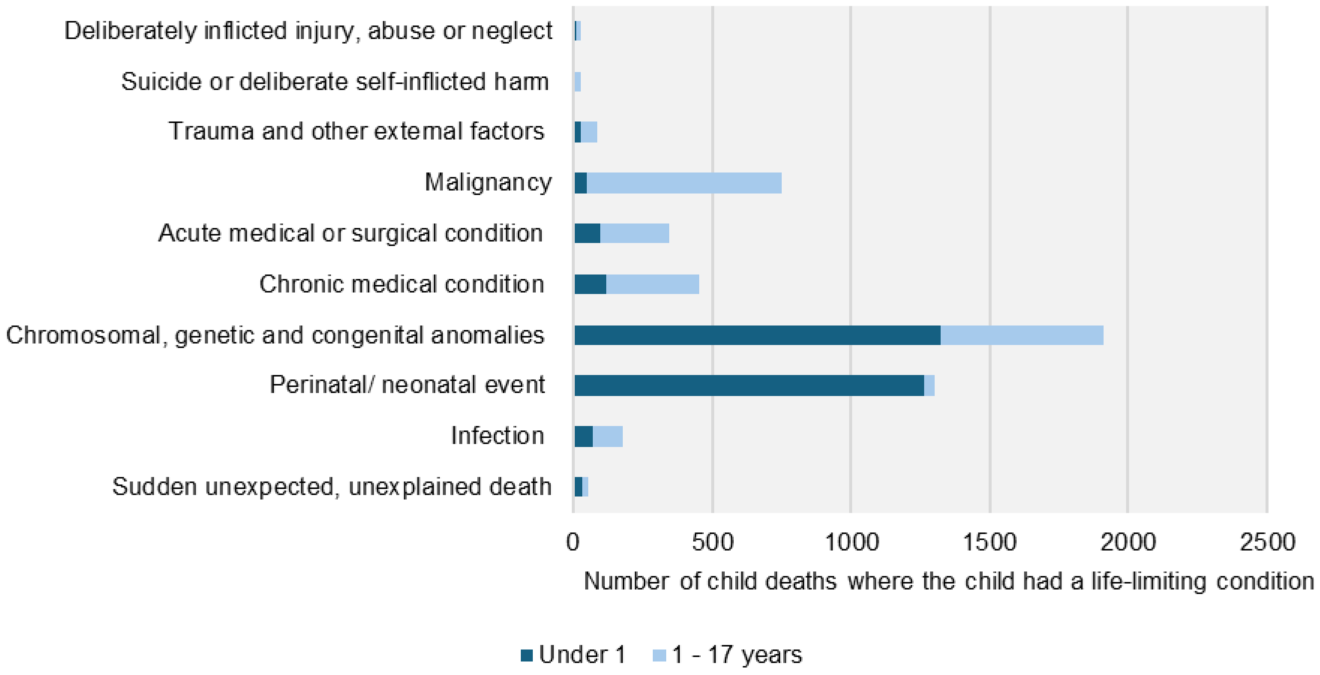
Figure 6: Number of infant (children under 1 year) deaths between 1 April 2019 and 31 March 2022 where the infant had a life-limiting condition, by gestational age at birth



CDOPs are required to assign a category to each death. Information on this categorisation process can be found in the child death analysis form. While more than one category can be applied, the *primary* category of death is the uppermost category of death selected.

CDOPs categorised the deaths of children with a life-limiting condition across all ten categories (Figure 7). The most common primary categories of death recorded by CDOP were *Chromosomal, genetic* and *congenital anomalies* (37% of deaths of children with a life-limiting condition), *Perinatal / neonatal event* (25%), and *Malignancy* (15%).

Figure 7: Number of child deaths between 1 April 2019 and 31 March 2022 where the child had a life-limiting condition, by primary category of death



Additional data is available in Data Tables, including breakdowns by sex, region, Integrated Care Board and mode of death.

2. National themes identified from CDOP reviews

This section focuses on learning from child death reviews on the provision of palliative care services and bereavement support. This includes information that was recorded as factors and learning on the CDOP analysis form. It reports the data from deaths where the supplementary reporting form 'death of a child with a life-limiting condition' was completed (n=2016; 39% of all deaths of children with a life-limiting condition). It is important to note that the learning in this section may potentially not be representative of all age groups and causes of death for children with a life-limiting condition. For example, a low proportion of reviews of neonatal (0–27 days) deaths and deaths due to a perinatal / neonatal event had a supplementary reporting form completed (15% and 12%, respectively), and therefore the learning from most of these deaths will not be reflected in this section.

Further information on limitations can be found in the Supporting Material.

Whilst child death reviews aim to identify any factors relating to the child's vulnerability, ill-health and death and to consider whether action should be taken in relation to these factors, CDOPs are also encouraged to report and acknowledge positive aspects of service delivery. There were many examples of excellent coordinated multi-disciplinary care, regular engagement with families, compassionate end of life care and bereavement support for the families of the children who died. However, this section focuses on the national themes of key issues identified by CDOPs on what further work is needed to improve services.

Appropriate parallel planning and engagement with palliative care

Parallel planning is where palliative care is offered in parallel with (at the same time) and alongside curative treatment or treatment aimed at significantly prolonging life[1]. It involves making multiple plans for care, to ensure care is dynamic and responsive to the changing needs of a child and their family and the fluctuating course of their condition. NICE Guideline NG61 recommends that parallel planning is used when developing plans for the care of a child with a life-limiting condition, to take account of the possible unpredictability during the course of the condition. Parallel planning has been highlighted as a vital component of care in helping to resolve disagreements between healthcare professionals and families[7].

There were 109 reviews which reported no evidence of appropriate parallel planning and no engagement with palliative care from healthcare professionals. Learning around improving parallel planning was reported in the

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7 Nuffield Council on Bioethics (2023)

CDOP reviews,often around the importance of earlier parallel planning and referral to the palliative care team. A palliative care plan may be offered and discussed with the perinatal team / treating team without a referral to specialist palliative care services, as per the BAPM Framework (2024) guidance on perinatal palliative care.

CDOPs reported missed opportunities to start parallel planning during previous hospital admissions and highlighted the need for increased knowledge of hospital teams. This would have helped in providing better support for families and health professionals when the child deteriorated. Timely engagement with palliative care helps effective symptom management, advance care planning, and bereavement planning. CDOPs highlighted cases where parallel planning and palliative care were offered but declined. This could be due to many different reasons, such as preference for acute intervention and curative treatment. It is possible that one factor may be how well healthcare professionals make the offer of palliative care. Embedding palliative care in clinical teams can improve the understanding that palliative care is an integral part of the overall care for the child.

Reviews also highlighted that if there is a diagnosis of a life-limiting condition during pregnancy, then there is a need to consider parallel planning and potential involvement of palliative care teams in the antenatal period. There were examples in the reviews of fragmentation of care, where those caring for the family after birth had not been involved during the pregnancy.

Named medical specialist

The supplementary data collection form asks the question whether the child had an end of life co-ordinator and an end of life medical lead. In 323 reviews, it was recorded that there was no end of life care co-ordinator for the child, and in 262 reviews, there was no end of life medical lead for the child. In 233 cases, there was no end of life co-ordinator nor end of life medical lead recorded.

NICE Quality Standard 160 states that children and young people with a life-limiting condition should have a named medical specialist responsible for leading and co-ordinating the care of the child. This is reiterated in the framework for palliative care in perinatal medicine by the British Association of Perinatal Medicine.

The importance of having a named medical specialist for each child was highlighted in the reviews. The absence of a named medical specialist may lead to poor co-ordination and oversight of care across services, difficulties in communication, lack of advocacy for the family, and potential missed opportunities to consider a long-term view of a child's health status, especially their trajectory towards the end of life. This was previously highlighted in the NCMD thematic report on children with a learning disability and autistic children.

Advance care planning

Advance care planning offers children, young people and their parents and carers the opportunity to plan future care, support and wishes and involves developing and recording an advance care plan (ACP). It is an important part of the care for children with life-limiting conditions as outlined in the NICE Guideline NG61 and should be in line with the NICE quality standards. During the antenatal period, it may include planning around antenatal care and wishes, e.g., a birth plan, feeding if the baby survives pregnancy, and choices around where the baby will be born.

As part of the advance care planning, discussions between the care teams, children, young people, and their families may include what should happen if resuscitation or life support may be required. Such discussions may happen gradually over many weeks or months and what is detailed in the plan is by agreement between the family and their care team. Each time a plan or an updated plan has been agreed it should be logged with the local ambulance service, so that they are aware of the family's wishes should they be called to the home. The advance care planning document should be appropriate to the circumstances and continually updated throughout the child's life.

CDOPs have identified 235 cases where there was no ACP in place at the time of the child's death. In 138 reviews, there was no symptom management plan in place.

The most common reasons recorded in the CDOP review were:

- Advance care planning was offered to the family, but it was declined by them.
- The healthcare professional thought advance care planning was not immediately relevant. The examples included: the child was felt not to be at the end of life stage; the child was not at a stage in their disease progression that advance care planning would normally be considered appropriate; the child had been well; there was an expectation that the child could be cured; the prognosis was unknown and the child thought to be well.
- The child died suddenly and unexpectedly or deteriorated rapidly.
- The child was at an acute stage of treatment – under ongoing treatment or assessment for treatment / surgery, e.g., assessed for or on the waiting list for an organ transplant. In some of the cases, palliative and end of life discussions were initiated, but the child died before an ACP document was put in place.
- No formal ACP was in place but there were symptoms management plans, Do not attempt cardiopulmonary resuscitation (DNACPR), palliative and end of life care planning, and key conversations (on wishes, goals, locations of care) had been carried out between medical teams, hospices and family.

In 66 reviews, it was recorded that the ACP was not discussed with the child or young person, mainly due to the child's or the child's family's wishes. It is important that advance care planning is specific to the needs of the child and family, and it was acknowledged that there may be many different reasons why the ACP was not discussed with the child.

Out of 285 neonatal deaths (a baby born alive who died under 28 days of age), 123 had an ACP in place at the time of death, and in 12, discussions were in progress at the time of death. In 20, there was no ACP in place at the time of the death, and the fact of an ACP or discussions was not known or not recorded in 130 cases. ACPs should be developed antenatally with parents and carers when a potentially life-limiting condition is diagnosed in a baby during pregnancy. CDOPs highlighted the importance of improved communication, early palliative care referral and conversations, as well as ensuring the ACP is shared with all teams and care providers.

CDOPs have identified cases where an ACP was in place at the time of the child's death but was not followed. Families may feel distressed and concerned for their child and decide to call emergency services for support in the moment of crisis. CDOPs identified that when such situations occur, the attending ambulance crew may not have access to the ACP, or, if it is found, the details on the family's wishes for resuscitation may not be quickly accessible. This can lead to full resuscitation being implemented and, in a few instances, to the police being contacted as part of the Sudden Unexpected Death in Childhood protocol. This causes considerable additional distress to a family who have taken care to plan a peaceful death with their care team.

CDOPs highlighted the importance that cultural beliefs are considered in all aspects of care planning, particularly in understanding cultural views on ACPs by different communities.

Prescribing or drug delivery issues

Effective symptoms management depends on the appropriateness and timeliness of the prescribed medications. Symptoms can change quickly, and patients may be cared for by different providers in multiple settings – in a hospital, hospice and / or at home. This requires continual planning, which should be well documented and clearly communicated between the different care providers, professionals, patients and families / carers.

Issues related to prescribing or problems with drug delivery were identified in 162 of the CDOP reviews. The following themes were identified:

- Difficulties with access to appropriate medication. This included issues with drug supply locally and / or nationally. There were cases of slow responses by GPs in prescribing, or pharmacies in dispensing, symptom management drugs. There were examples of situations where GPs were not able to prescribe certain drugs, such as specialist medicines that can only be prescribed by specialist clinicians (also known as red drugs).
- Medication administration, prescribing or dispensing errors. The records identified delays in take home medications, medications not appropriately dispensed, and patients being transferred without an updated medical report or list of medications.
- Challenges with supply of medications from GPs.
- Challenges with administration of medication in the hospice due to lack of appropriate protocols for IV fluids to be delivered in this setting, or the hospice not delivering total parenteral nutrition.
- Issues with administration of subcutaneous drugs or fluids at home. Reported issues included the lack of 24-hour nursing support over the weekends for setting up syringe drivers at home, and delays in the delivery of the syringe driver when first commenced.
- Insufficient skill mix in prescribing. Reviews highlighted that more education is required on end of life drugs. For instance, training is needed for GPs and general paediatrics ward medical teams on symptom control prescribing and advance care plans.

Use of cold bedroom or cot after death

Cooling facilities (e.g., cold bedroom, cold cot / blanket) can help families with the initial grieving process immediately after a child's death. These facilities can provide families with time to start to process their loss[8].

In 483 of the reviews, it was recorded that cold bedrooms or cold cots were not used after the child's death. In most of these cases, the families were offered the use of a cold bedroom/cot, but families did not wish to use them. There could be many reasons why families did not wish to use the facilities, including religious or cultural preferences.

In 32 reviews, cold bedrooms or cots were not used due to the requirement for a post-mortem examination or coroner investigation.

There were 16 reviews where the restrictions due to the COVID-19 pandemic meant that these facilities were not offered, and a further 20 cases unrelated to the pandemic where the cooling facilities were not offered, not available or not working.

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[8] Hackett et al (2021)

Commissioning and funding of palliative care services

Inconsistent funding arrangements for the delivery of paediatric (including perinatal / neonatal) palliative care across regions of the country has been previously highlighted[9]. This was also recently highlighted in the Built to Last? The state of children's palliative care in 2025 report. There were 54 reviews where gaps in palliative care service provision were recorded by CDOPs. These related to situations where the service was either not commissioned or not funded. Most of these reviews highlighted that, in some regions, there is a lack of routine 24-hour access to community nursing services, and out of hours palliative care is not a fully commissioned service for the children's community nursing team.

NICE Quality Standard 160 states that any child approaching the end of their life and being cared for at home should have 24-hour access to both paediatric nursing care and palliative care advice. Where possible, services should ensure that children and young people can be cared for at their preferred place of care and die in their preferred place of death. This could include a service that provides extended hours for face-to-face services, with 24-hour access to phone support from a palliative care specialist. Where there was no access to community nursing services or palliative care support, this gap in service meant that the wishes of the child or family to be at home at the time of death could not be fulfilled. This potentially impacted on the quality of care and support that the child and the family received at the end of life. CDOPs also reported that access to 24-hour end of life care in the days prior to death would have enabled improved symptom management in the home and could have avoided attendance at the emergency department, or hospital admissions.

Reviews often acknowledged that many of the teams involved had been supporting children and their families solely on a good will basis, with healthcare professionals often working outside their normal working hours. This was necessary to fill gaps in services, to provide support and advice, and to enable the child to die in their location of choice. Such additional work placed significant responsibility on teams, often without any formal recognition, which potentially impacted on the resilience of services and on the families involved.

Even where out of hours services were commissioned, reviews highlighted that, due to limited capacity, sometimes these had to be requested by parents. Capacity issues of existing services were noted, with difficulties in staff recruitment, retention and skill base. The challenge of ensuring a safe and sustainable service was recorded. The Association for Paediatric Palliative Medicine and the Royal College of Paediatrics and Child Health have previously highlighted concerns about workforce capacity and insufficient deanery national training numbers are allocated to junior doctors wishing to sub-specialise in paediatric palliative care. The Built to Last? report recommends that the UK Government should expand the children's palliative care workforce, to include increased spending on specialist paediatric palliative medicine GRID and SPIN training.

Palliative care services were not always available in hospital trusts, including tertiary specialist children's hospitals. CDOPs highlighted the need for a funded paediatric palliative care service in some hospitals, and the need to ensure training in the management of syringe drivers for subcutaneous infusions, for ward staff. Syringe driver protocols should be aligned between hospitals, hospices and community services, as part of a managed clinical network (managed clinical networks are also recommended in NG61).

Bereavement support for families

When a baby, child or young person is approaching the end of life, the available pre-bereavement and bereavement support options should be discussed with their parents or carers. Where information was available (n=469), bereavement support was offered in 455 cases. Bereavement support was not offered in 14 of the reviews.

Most of the learning from the reviews was related to issues with communication and the need to ensure clear communication between teams before and after the death of the child. A collaborative approach to bereavement support is required to ensure duplication is avoided and gaps are identified.

A key worker must be appointed for all bereaved families in line with the Child Death Review Statutory & Operational Guidance. It is important that there is collaboration and clear communication between hospice, hospital (including palliative care, neonatal and midwifery bereavement teams) and community staff when identifying an appropriate lead bereavement key worker.

CDOPs also highlighted the need for timely referral to palliative care for parallel planning which supports better planning and communication around bereavement support. Where there is a diagnosis of a life-limiting condition during pregnancy, it is important that the bereavement team is informed antenatally, to improve co-ordination and involvement in care planning. Bereavement support may be provided by various different professionals including bereavement midwives, hospice teams and charities. For neonatal deaths, neonatal nurses may provide this during the neonatal admission, sometimes antenatally.

There were also issues in ensuring the offer of bereavement support was appropriately documented, bereavement checklists were completed, and that the needs of wider family members were met. There were challenges in supporting bereaved families during the COVID-19 pandemic, where bereavement support needed to be adjusted to comply with restrictions.

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[9] Papworth et al (2023)

3. Recommendations

Commissioning

- Children and young people with life-limiting conditions should be cared for by a defined multi-disciplinary team that enables assessment, management, and 24-hour telephone advice 7 days a week. NHS England has developed statutory guidance to support Integrated Care Boards with their duty to commission palliative care services and service specifications for palliative and end of life care for children and young people.

  Recommendation 1: Review commissioning arrangements to ensure all infants (including those who are preterm), children and young people with life-limiting conditions have 24-hour access to community nursing teams, specialists in paediatric palliative care, and other appropriate healthcare professionals as required, and especially at the end of life.

  Action: Integrated Care Boards in collaboration with: Children and Young People Palliative Care Operational Delivery Networks, Neonatal Operational Delivery Networks, Paediatric Critical Care Operational Delivery Networks, Surgery in Children Operational Delivery Networks

- All families should have timely bereavement support, before and after a death, as appropriate. Bereavement support should be flexible and holistic, ensuring the individual needs of each family, including siblings, are met.

  Recommendation 2: Ensure all bereaved families are allocated a key worker, in line with the Child death review statutory and operational guidance. The key worker post should be funded and embedded appropriately as per the guidance.

  Action: Integrated Care Boards, Local Authorities, NHS providers

Education

- All parents and carers of children and young people with life-limiting conditions require information and opportunities to discuss parallel planning which should be documented in an advance care plan.

  Recommendation 3: Ensure all named medical specialists working with infants, children and young people receive and complete appropriate training in parallel planning and documenting advance care plans (e.g., the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) form and the Children and Young Person's Advance Care Plan (CYPACP) document).

  Action: The Royal College of Paediatrics and Child Health, Association of Paediatric Palliative Medicine, The College of Paramedics

- All advance care plans should contain up to date and easily accessible information on resuscitation that can be found quickly in high pressure situations.

  Recommendation 4: Integrated Care Boards working with care providers looking after children with life-limiting conditions should ensure that the ReSPECT / resuscitation document is easily visible. In hospital trusts this might include adding it to the 'banner' bar of the electronic patient record.

  Action: All hospital trusts

Medicines

- Children and young people with planned end of life care at home require timely access to oral and subcutaneous medications to relieve distressing symptoms.

  Recommendation 5: Ensure timely access to essential medications needed for the delivery of end of life care at home. This should include parenteral medication for subcutaneous infusions and medications needed off label or beyond their licence (as this is frequently the case in paediatric palliative care).

  Action: Integrated Care Boards, Royal College of General Practitioners, Royal Pharmaceutical Society

4. Next steps and future priorities

Analysis in this report has identified a key area where further research is needed:

- What are the barriers to providing timely access to safe and effective medications for delivery of end of life care in the home setting?

Further research recommendations related to the themes highlighted within this report have previously been made in NICE Guideline NG61, including:

- What is the impact of offering timely perinatal palliative care on the experience of bereaved families?
- When planning and managing end of life care what factors help children and young people with life-limiting conditions and their parents or carers to decide where they would like end of life care to be provided and where they prefer to die?
- What is the effectiveness of a home based package of care as opposed to hospital or hospice care?

NCMD
National Child Mortality Database

Knowledge, understanding and learning to improve young lives

National Child Mortality Database (NCMD)

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