

About us

Together for Short Lives is the UK charity that, together with our members, speaks out for children and young people who are expected to have short lives. Together with everyone who provides care and support to these children and families, we are here to help them have as fulfilling lives as possible and the very best care at the end of life. We can't change the diagnosis, but we can help children and families make the most of their time together.

The Chancellor of the Exchequer's Budget on 8 March is an important opportunity for the government to help families of children with life-limiting or life-threatening conditions, who are some of the most vulnerable and disadvantaged in our country. Many parent carers are forced to juggle work responsibilities and care for other children as well as providing round the clock support for their seriously ill child. Some only just manage, and need an active government to step in to help them stay resilient, to make sure they do not break down or reach crisis point. Our representation sets out what we the Chancellor can do to better support children who need palliative care as part of the shared society agenda.

The Economic Case for investing in Children's Palliative Care

In December, the National Institute for Health and Care Excellence (NICE) published a new clinical guideline 'End of life care for infants, children and young people with life-limiting conditions: planning and management'.¹ **NICE calculate that by investing £12.7million in implementing the guidance, non-cash savings worth £34.7million would be released back into the NHS in England.**² NHS England should invest in managed clinical networks of the services which seriously ill children need, including community children's nursing, children's hospices and NHS acute teams providing children's palliative care.

The Societal Case for investing in Children's Palliative Care

Hearing the news that your child has a life-limiting or life-threatening condition and is likely to die young is completely devastating. For tens of thousands of families in the UK this is the reality. These children have very complex and unpredictable conditions and often need round the clock care, seven days a week. There are 49,000 children and young people in the UK with life-limiting or life-threatening conditions, a number which is growing as a result of advances in medical technology and better care. Unfortunately, this small population is

"It's a minefield and you get frightened going through it. Services don't join up and people don't explain things to you. They don't tell you what all the services actually do. By the time I had made it all fit together my child had passed away - that makes me sad that he could have had so much more out of life".

A bereaved parent of a child who had a life-limiting condition

¹ NICE (2016). End of life care for infants, children and young people with life-limiting conditions: planning and management. Available to download from: <http://bit.ly/2g9nIWA>.

² NICE (2016). End of life care for infants, children and young people with life-limiting conditions: planning and management 'Resource Template'. Available to download from <http://bit.ly/2k4V2jZ>. This figure for the whole of England was calculated using the 'Population & resource summary' tab.

largely misunderstood, they are inappropriately treated like 'mini adults' and therefore are denied the care and support they need for both a quality of life and a quality of death. Those that provide the necessary services and support to these children and families are facing cuts in funding (61% reduction in local authority funding last year) when the cost of providing complex care increases (up 10% this year).³ We are calling on the Treasury to help bridge this funding gap and ensure that funding parity is achieved between children's and adult's palliative care. This gap should not be tolerated - a shared society should view the life of a child as valued as much as the life on an adult.

Summary of our proposals

We are asking the Budget to invest in children's palliative care services

1. **Adequately fund children's palliative care to meet demand:** We are asking the Government to reverse the 61% cut in funding for children's palliative care charities from local authorities - and increase the value of the children's hospice grant to meet growing demand and complexity of care needed by children and families.⁴ Currently children's palliative charities only receive 22% of their funding from the state while adult hospices receive 33% - this discrepancy must be addressed.⁵ The government should address the post code lottery and make sure that clinical commissioning groups and local authorities are transparent and are held to account in how they fund children's palliative care.
2. **Giving young people dignity and respect - bridging the cliff edge in care between children's and adult services:** Seed fund new services which provide palliative care that meets the age and developmental needs of young people with life-limiting or life-threatening conditions. These services should also bring about smooth transitions from children's to adults' palliative care.
3. **Supporting managed clinical networks (MCNs):** The National Institute for Health and Care Excellence (NICE) recommends that services should be based on managed clinical networks should collaborate in planning and providing care.⁶ MCNs should build a strategic and joined up approach to children's palliative care across health and social care, across the statutory and charitable sectors and in different care settings. We are calling on the government to invest in making sure that MCNs are in place across England.
4. **Ensuring nursing care today and tomorrow:** It is vital that we have in place a sustainable children's palliative care workforce. Two thirds of children's palliative care charities report a shortage in nurses which is resulting in a reduced offer of care to families. Nurse vacancy rates are currently at 10%, higher than the NHS nurse vacancy rate (7%). August 2017 will mark the twentieth anniversary of the death of Diana, Princess of Wales. In the year following her death, the government established the Diana community nursing teams in her honour, which were set up to ensure children with life-limiting or life threatening conditions – and their parents – are given the support that they need at home. We call on the government to invest in community nursing teams to make sure that every seriously ill child and young person can receive palliative care when and where they need it. We also call on the government to protect the existing Diana teams

³ Together for Short Lives (2016). On the brink: a crisis in children's palliative care funding in England. Available to download from: <http://bit.ly/2f7HowK>.

⁴ Ibid.

⁵ Ibid.

⁶ NICE (2016). End of life care for infants, children and young people with life-limiting conditions: planning and management. P 32. Available to download from: <http://bit.ly/2g9nlWA>.

across the UK. Such a commitment would be a fitting way in which to mark this important anniversary.

We are asking the Budget to invest in support for families who have a child with a life-limiting or life-threatening condition

5. **Preventing family breakdown:** We know that services need to be better organised around families and not institutions so it easier for them to navigate the system and access the care and support they need. Government should renew its commitment to funding short breaks to provide respite care for families so that they have time to recharge their batteries. This would reverse the trend of family breakdown.
6. **Lifting the baby benefit bar:** We call for funding to allow families with children under three with life-limiting or life-threatening conditions to access the mobility component of the disability living allowance so they can purchase a specially adapted vehicle to carry life supporting equipment. Currently the benefit is only available to children aged three and over. This unfairly penalises children under three.
7. **Care and compassion in bereavement:** We support calls to allocate funds to make sure that bereaved parents have a right to a period of statutory paid leave following the death of their child. We also support calls for the government to exempt child deaths from the new death certification fees structure. Families who provide long-term care for their child suffer enormous financial pressures while their child is alive and the proposed new fee will unfairly add to these pressures.

More detailed information about each of our asks is set out below:

Section A: Investing in children's palliative care services

Adequately funding children's palliative care to meet demand

1. In 2011, a government-commissioned review of funding arrangements for palliative care found that the lack of a clearly defined funding model has led to a wide variation in the level of state funding provided to services, including children's hospices.⁷ The only income that children's hospices receive which is committed to by NHS England is an annual £11 million grant, which is split between 36 children's hospice charities.
2. The number of children and young people with life-limiting or life threatening conditions is increasing. For example, a 2015 report showed a 50% increase over a ten-year period in the number of children and young people with life-limiting or life threatening conditions in Scotland.⁸ This is a dramatic rise; if replicated across the UK then the number of children and young people with life-limiting or life threatening conditions could be much greater than the current estimate of 49,000.
3. Together for Short Lives' survey of voluntary sector children's palliative care providers shows that their average charitable expenditure increased by 9.7% in real terms between 2014/15 and 2015/16.⁹ This increased spend reflects the growing complexity and demand for children's palliative care.
4. As the children's hospice grant remains static at £11 million and children's hospices face increasing costs to support children with life-limiting or life threatening conditions, the grant is gradually diminishing as a proportion of children's hospices' charitable expenditure.
5. Together for Short Lives' survey of voluntary sector children's palliative care providers shows that the state's contribution to the cost of providing children's palliative care in the voluntary sector fell. It was 22% in 2015/16 compared to 23% in 2014/15 and 27% in 2013/14.
6. The contribution that VCS organisations can expect towards the cost of providing children's palliative care increasingly reflects a postcode lottery. When taking the NHS children's hospice grant and funding from CCGs and local authorities into account, the standard deviation in local authorities' contributions to the cost of providing children's palliative care in the voluntary sector has risen to 12% in 2015/16 from 10% in 2014/15. The maximum contribution received by a VCS children's palliative care provider in 2015/16 was over half (53%), while the lowest was 2%.¹⁰
7. Over (59%) of VCS children's palliative care providers would be forced to reduce their services if the children's hospice grant was no longer available.¹¹ Over two thirds (70%) said that they would be most likely to cut short breaks, followed by bereavement support (41%), family support services, complementary therapies and day services/outpatient clinics (all 37%).

⁷ Hughes-Hallett T, Craft A and Davies C (2011). Palliative care funding review - creating a fair and transparent funding system; the final report of the palliative care funding review. Available to download from: <http://bit.ly/XQBIE7>.

⁸ Fraser et al. (2015). Children in Scotland requiring Palliative Care: identifying needs and numbers. Available to download from: <http://bit.ly/1Krn2EU>.

⁹ Together for Short Lives (2016). On the brink: a crisis in children's palliative care funding in England. Available to download from: <http://bit.ly/2f7HowK>.

¹⁰ Ibid.

¹¹ Ibid.

8. If children's hospices did not exist, then the cost of care for these children would fall directly to the NHS with additional costs relating to 24/7 support and care and bed use.
9. **We ask that the government increases the value of the children's hospice grant to reflect the fact that demand for this care is increasing and life-limiting and life-threatening conditions are becoming more complex. Without this support, responsibility for care would shift directly to the NHS.**
10. Together for Short Lives made a series of freedom of information requests of local authorities and clinical commissioning groups (CCGs) in England during April 2016, which sought to establish how well these organisations are planning, funding and monitoring care for children with life-limiting or life-threatening conditions.¹² Although we asked each CCG and local authority how much they spend on short breaks, step-down care, end of life care and transition, very few were able to determine this spending.
11. **We call on government to help build greater transparency, confidence and accountability by requiring CCGs and local authorities to report on the way they plan and fund children's palliative care.**

Giving young people dignity and respect - bridging the cliff edge in care between children's and adult services - transition

12. Medical advances mean more young people with a range of life-limiting or life threatening conditions are living into adulthood. There are 56,000 young adults aged between 18 and 40 with life-limiting or life threatening conditions and this figure continues to grow.¹³ The transition from the comprehensive care offered by children's services to unfamiliar adults' services can be daunting as they must forge relationships with new agencies and professionals. For many young people with life-limiting or life threatening conditions, this transition coincides with a rapid decline of their condition and eventual death. As such, they have specific needs which differ from both younger children and older adults, yet there is a lack of age and developmentally-appropriate palliative care services for these young adults.
13. Specifically, there is a dearth of services which can offer short breaks to young people with the most complex health needs. This is a market failure, whereby the services available do not match the needs of these young people. We believe the government should intervene to correct this failure and step in where the market cannot deliver, by providing seed funding to stimulate voluntary sector services to provide age and developmentally-appropriate services to this group of young people. This earlier investment will help avoid a 'cliff edge in care' and the associated wellbeing costs.
14. **We would like the government to commit to provide seed-funding to stimulate voluntary sector organisations to provide age and developmentally appropriate services to young people with life-limiting or life threatening conditions - and which bring about smooth transitions from children's to adult services.**

Supporting managed clinical networks (MCNs)

¹² Together for Short Lives (2016). Commissioning children's palliative care in England. Available to download from: <http://bit.ly/2iAOH3z>.

¹³ Fraser LFK, Miller M, Aldridge J, PA, Parslow RC (2013). Prevalence of life-limiting conditions in young adults in England 2000-2010; final report for Together for Short Lives. Available to download from: <http://bit.ly/1z24VQQ>

15. The National Institute for Health and Care Excellence (NICE) recommends that children's palliative care services should be based on managed clinical networks, which coordinate and the planning and provision of providing care in local areas.¹⁴
16. Managed clinical networks help to build a strategic and joined up approach to children's palliative care across health and social care services and bring together statutory and charitable providers. This approach has already been adopted in Wales, where the All Wales Managed Clinical Network works to support children and their families with life-limiting or life threatening conditions by facilitating the delivery of appropriate specialist care in whatever clinical environment the child is located.¹⁵
17. In its new clinical guideline 'End of life care for infants, children and young people with life-limiting conditions: planning and management', NICE calculate that by investing £12.7million in implementing the guidance, non-cash savings worth £37.7million would be released back into the NHS in England.
18. Managed Clinical Networks should build on the ten established children's palliative care networks in England (East Midlands; East of England; London; North East; North West; South Central; South East Coast; South West; West Midlands). This would provide a coordinated and collaborative approach to children's palliative care delivery in each of the regional areas. Based on our experience from the successful neonatal Managed Clinical Networks, we envisage that each network would require a minimum of a band 8A/8B network manager; 0.2wte senior nurse and 0.2wte senior medic. If this is applied to each of the ten networks, we estimate that the overall investment for the first year will be £1million. As the first year will require a great deal of coordination and administrative work, the second and third years of operation will require less staff time and so would require approximately £750,000 and £500,000 respectively. The ten networks would also require national cooperation – bringing together the leaders of each network. Given our position as a membership organisation for those working in children's palliative care, we propose that Together for Short Lives assumes this national coordinator role.
19. **We would like the government to commit to investing £1million to establish children's palliative care managed clinical networks, followed by £750,000 and £500,000 in the following two years, to improve coordination and collaboration between statutory and voluntary services in a range of care settings, as recommended by NICE.**

Ensuring nursing care today and tomorrow

20. Statutory and voluntary sector children's palliative care services require a sustainable nursing workforce.
21. Our research shows that 10% of nursing posts within voluntary sector children's palliative care providers are vacant – higher than the NHS average nursing vacancy rate (7%).¹⁶ This is resulting in reduced care for families such as: fewer available beds in children's hospices; a reduction in short breaks on offer to families; and preventing children from being cared for and forming meaningful relationships with their nurse as agency nurses change from day to day.

¹⁴ NICE (2016). End of life care for infants, children and young people with life-limiting conditions: planning and management. P 32. Available to download from: <http://bit.ly/2g9nIWA>.

¹⁵ Together for Short Lives. All Wales Managed Clinical Network. Available at: <http://bit.ly/2k3Vflc>.

¹⁶ Together for Short Lives (2015). Nurse Vacancy Survey -2015. Available to download from: <http://bit.ly/1p88UMo>.

22. We are concerned that the removal of student bursaries for nurses, midwives and allied health professionals could have an adverse effect on the number of students choosing to study these courses. Although under the current UK government proposals students would still have access to funding through student loans, we share the concern of the Royal College of Nursing that potential students may be put off by the prospect of accruing more long-term debt.¹⁷ We call on the government to reverse the decision to remove student bursaries.
23. As the United Kingdom prepares to leave the European Union, we support the Royal College of Nursing's call to make sure that there is a workforce strategy that maintains and grows the domestic health and social care workforce; preservation of the rights of European Economic Area nationals currently working in the sector; appropriate education and regulatory frameworks in place to ensure continued recruitment from Europe to meet our immediate recruitment challenges.¹⁸
24. **We would like the government to make sure that there is a sustainable children's palliative care workforce to meet the increasing care needs for children and young people. To do so, we call on the government to reverse its decision to remove student nursing bursaries and to properly reimburse voluntary sector organisations which deliver placements for nursing students during their training.**
25. Children with life-limiting or life threatening conditions also need to get the support they need, when they need it, in their communities from community children's nursing teams. In 2011 the Department of Health described community children's nurses as the 'bedrock of the pathways of care' for four groups of children, which included children with life-limiting and life-threatening illness.¹⁹ However, our research shows that while 94% of CCGs commission community children's nursing teams, over a quarter of CCGs do not commission these services out of hours and at weekends – leaving families isolated and unable to access care when they need it.²⁰
26. The Royal College of Nursing (RCN) recommends that for an average-sized district, with a child population of 50,000, a minimum of 20 whole time equivalent (WTE) community children's nurses are required to provide a holistic community children's nursing service.²¹ The Office of National Statistics estimates that there are 13,770,873 children aged 0-18 in England.²² If the RCN recommendation were to be met, this would therefore require approximately 5,508 community children's nurses. There are currently just 535 community children's nurses in England.²³

¹⁷ RCN (2016). RCN response to the Department of Health consultation: Changing how health care education is funded. Available from: <http://bit.ly/2jCxDTz>.

¹⁸ Royal College of Nursing (2016). Submission to the Health Select Committee inquiry on the priorities for health and social care in the negotiations on the United Kingdom's withdrawal from the European Union. Available to download from: <http://bit.ly/2iFTRv4>.

¹⁹ DH (2011). NHS at Home: Community Children's Nursing Services. P3. Available to download from <http://bit.ly/10zZtZV>.

²⁰ Together for Short Lives (2016). Commissioning children's palliative care in England. Available to download from: <http://bit.ly/2iAOH3z>.

²¹ RCN (2014). The future for community children's nursing: challenges and opportunities. P.10. Available to download from: <http://bit.ly/1QgLhZb>.

²² ONS (2016). Population Estimates Analysis Tool: Mid-2015. 'Persons UK' tab. Available to download from: <http://bit.ly/2iJOTgS>.

²³ NHS Digital (2016). NHS Workforce Statistics - September 2016, Provisional statistics: Staff Group, Area and Level. Available to download from: <http://bit.ly/2j2srhm>.

27. August 2017 will mark the twentieth anniversary of the death of Diana, Princess of Wales. In the year following her death, the government established the Diana community nursing teams in her honour, which were set up to ensure children with life-limiting or life threatening conditions – and their parents – are given the support that they need at home. We call on the government to invest in community nursing teams to make sure that every seriously ill child and young person can receive palliative care when and where they need it. We also call on the government to protect the existing Diana teams across the UK. Such a commitment would be a fitting way in which to mark this important anniversary.
28. **We would like the government to provide immediate funding to the Department of Health to address the massive shortfall in community children's nurses in England - and to protect existing Diana nursing teams.**

Section B: Investing in support for families who have a child with a life-limiting or life threatening condition

Lifting the baby benefit bar

29. The government's disability living allowance (DLA) benefit recognises that families of disabled children over the age of three may need financial support to access appropriate transport. Families can apply for the DLA 'mobility component', available at a higher and lower rate.
30. In setting the lower age limit for entitlement, the Department of Work and Pensions (DWP) considered views of medical advisors that the majority of children could walk at the age of 2½. By the age of 3 it was realistically possible in the majority of cases to make an informed decision as to whether an inability to walk was the result of disability.
31. However, babies and young children under the age of three with life-limiting or life threatening conditions often depend on ventilators, large equipment or other types of technology to stay alive. This equipment is big and heavy. Some babies and young children have permanent wheelchairs and are not able to use buggies suitable for well children of the same age. These wheelchairs are heavy because of the equipment and they need to be fixed into a vehicle.
32. These children and their families have been unable to receive the support they need because of the technical qualifying criteria for welfare support. Their additional mobility needs are already recognised in other areas of government policy: children under the age of three who depend upon bulky medical equipment, or need to be near their vehicle in case they need emergency medical treatment are eligible for a blue parking badge. Giving this group of children access to the mobility component would enable their families to access an adapted car.
33. **We call on the government to extend mobility payment for families of babies and young children under the age of three who depend on bulky medical equipment or who need to stay close to their vehicle in case of a medical emergency. Such payments, unfairly, only begin aged three. The extended payments should be equal to the value of the higher rate of the DLA mobility component.**

Table 1: The number of children that a new scheme would need to apply to and the cost of introducing it

Number of children/ cost	Description
2119	Number of children in England under the age of three who are dependent upon bulky medical equipment, or need to be near their vehicle in case they need emergency medical treatment'
104	Number of children in Wales under the age of three who are dependent upon bulky medical equipment, or need to be near their vehicle in case they need emergency medical treatment'
2223	England and Wales total
£ 57.45	Higher rate DLA mobility component for children
£ 127,711	Per week cost of extending mobility component to children under the age of three in England and Wales who are dependent upon bulky medical equipment, or need to be near their vehicle in case they need emergency medical treatment'
£ 6,640,990	Per year cost of extending mobility component to children under the age of three in England and Wales who are dependent upon bulky medical equipment, or need to be near their vehicle in case they need emergency medical treatment'

Preventing family breakdown

34. Short breaks provide vital respite care for families so that they have time to recharge their batteries. This is essential to prevent family breakdown among families of children with life-limiting or life threatening conditions, who often care for their child 24/7. Currently, 36% of families who have a child with a life-limiting or life threatening condition will suffer family breakdown and the government must act to reverse this trend.²⁴
35. We were disappointed that the government's new 2% Council Tax precept that local authorities can levy is to be limited to adult social care. With local authorities struggling to cope with rising demand, children's social care services that families rely on to keep going, including short breaks, will become much more scarce.
36. Research by Together for Short Lives shows that nearly a quarter (23%) CCGs and one in seven (14%) local authorities do not commission short breaks for children and young people aged 0-25 who have life-limiting or life threatening conditions.²⁵ This means that many local authorities are failing to provide vital short breaks to children and families - potentially contravening their legal duty to provide short breaks for disabled children.
37. Our survey of VCS children's palliative care providers in England found that local authorities' contribution to the cost of providing children's palliative care in the voluntary sector fell significantly by 61% between 2014/15 and 2015/16. This means that local authorities contribute just 1% to the charitable costs incurred by VCS children's palliative care organisations.

²⁴ Steele R. (2000) Trajectory of certain death at an unknown time: children with neurodegenerative LTC illnesses. Cancer Journal of Nursing Research 32, 49-67.

²⁵ Together for Short Lives. (2016). Commissioning children's palliative care in England. Available to download from: <http://bit.ly/2iAOH3z>.

38. In December 2010 the government committed £800m in funding over four years for short breaks to make sure local authorities could meet their legal duties under The Regulations for Breaks for Carers of Disabled Children 2011 over the course of the parliament.²⁶ However, Every Disabled Matters (EDCM) partnership found that 58% of local authorities who responded to their freedom of information requests had cut their short breaks spending during this period, by an average of 15%.²⁷ This has a direct impact on families - the same survey found that only 9% of respondents to the survey of parent carers agreed or strongly agreed that families with disabled children can access the short breaks they need. We would like the government to repeat the £800m funding, provide guidance to local authorities on how this funding should be used and ensure that they transparently share how that funding is used.
39. The inequity of support for children with life-limiting or life threatening conditions in England results in unfairness, whereby a family in one part of the country may be unable to access the short breaks that they need, while others are able to. We believe the government should intervene to make sure that local authorities are fulfilling their short breaks duties in order to restore fairness.
40. **We ask that the government commits to a continued investment of £200m per year for local authorities to fund children's social care and to enable them to meet their short breaks duties under The Regulations for Breaks for Carers of Disabled Children 2011. Furthermore, the Department for Education should monitor spending by each local authority to ensure more equitable short breaks provision for children with life-limiting or life threatening conditions across England.**

Care and compassion in bereavement

41. The Parental Bereavement Leave (Statutory Entitlement) Bill 2016-17 was introduced by Will Quince MP in September 2016.²⁸ This Bill would provide bereaved parents with two weeks' statutory paid leave following the death of their child. There is currently no statutory paid leave provision for bereaved parents.
42. **Together for Short Lives supports the Parental Bereavement Leave (Statutory Entitlement) Bill 2016-17. We would like government to allocate funds to make sure that bereaved parents have a right to a period of statutory paid leave following the death of their child.**
43. Together for Short Lives supports the principles behind the proposed death certification reforms.²⁹ We are pleased that the new system supports urgent death certification for expected deaths of children in hospitals, so that families can move them home or closer to home – i.e. a children's hospice. We are pleased that feedback from the pilot sites shows that this urgent certification process is manageable and we urge the Department of Health to maintain this concession.

²⁶ Department for Education (2010). Government announces £800 million to support families. Available at: <http://bit.ly/2kaaT55>.

²⁷ Every Disabled Child Matters (2015). Short Breaks in 2015: An uncertain future. Available to download from: <http://bit.ly/2iJ1p04>.

²⁸ Parental Bereavement Leave (Statutory Entitlement) Bill 2016-17. Available at: <http://bit.ly/2jGvCfA>.

²⁹ Department of Health (2016). Introduction of Medical Examiners and Reforms to Death Certification in England and Wales. Available to download from: <http://bit.ly/2jZnOmb>.

44. However, we are concerned that the new system as proposed will result in an additional cost for families whose child has died, as they will be liable to pay the medical examiner fee, regardless of whether their child is buried or cremated.
45. Families who provide long-term care for their child suffer enormous financial pressures while their child is alive, including: a lack of opportunity to work; increased household bills; purchasing new equipment.³⁰
46. In addition to this, they face further loss of income when their child has died due to the cessation of benefits, debt repayment, and funeral costs. We believe that the proposed new fee will unfairly add to these pressures. Furthermore, there are fewer than 4,000 child deaths in England³¹ each year and approximately 200 in Wales³² and this exemption would therefore represent less than 1% of the approximately 500,000 deaths that are registered in England and Wales each year.³³ **If the fees are set at the proposed level of £81, then this exemption will cost approximately £340,200.**
47. **We urge the government to exempt child deaths from the new fees structure. Though this would have minimal financial impact on the new death certification scheme, it would prevent the new fees structure from adding to the enormous financial pressures that families face when their child dies.**

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³⁰ Together for Short Lives (2016). Introduction of Medical Examiners and Reforms to Death Certification consultation: submission from Together for Short Lives. Available to download from: <http://bit.ly/1rtqawz>.

³¹ Department for Education (2016). Child death reviews: year ending 31 March 2016. Available to download from: <http://bit.ly/2jwwpA5>.

³² Reilly, R., Heatman, B. (2015). Child death review programme: Annual report July 2015. Available to download from: <http://bit.ly/2il7PaV>.

³³ ONS (2015). Deaths Registered in England and Wales: 2014. Available from: <http://bit.ly/2k3YRdh>.