

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.

The Chancellor of the Exchequer's Budget on 22 November 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 the opportunity for the Chancellor to help better support children who need palliative care and begin to realise the ambition of a shared society which supports those who are only just about managing.

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

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. 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 because of advances in medical technology and better care. Unfortunately, this small population is largely misunderstood, they are often inappropriately considered as 'mini adults' and are denied access to the right 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 also facing cuts in funding (61% reduction in local authority funding last year) when the cost of providing complex care is increasing (up 10% this year).³ We are calling on the Treasury

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.

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>.

to bridge this funding gap and to 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.

"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

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 £25 million per annum** 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, as it has been in Scotland where the government has allocated £30million over 5 years for children's hospices so there is parity with funding for adult hospices.**⁵ The government should also address the post code lottery in funding and support and make sure that clinical commissioning groups and local authorities are transparent and are held to account in demonstrating 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:** The transition between children's and adults care is described by young adults as like facing a cliff edge. We would like the government to 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 managed clinical networks should be supported to help collaboration 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 this recommendation is realised and 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 11%, in line with the NHS nurse vacancy

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>.

rate (11%). To address this shortage, we call on the government to reverse its decision to properly reimburse voluntary sector organisations which deliver placements for nursing students during their training

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. We regularly hear families say that caring for a child with a life-limiting condition can be isolating and, at times, very lonely, leading to breakdowns in their relationships and social life. The 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 help reduce the incidence of family breakdown.
6. **Lifting the baby benefit bar:** We are calling for fair 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 welcome the government's announcement that it is to support a Private Members Bill to introduce a legal right to bereavement leave for parents whose child has died. We would like the government to make sure that this bereavement leave is flexible so that parents do not have to take it in one week 'blocks'. We also ask that the government takes steps to make sure that self-employed people can receive the same statutory support as those who are classed as employees.

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. To address this increase in demand the Scottish Government, have allocated £30million over 5 years for children's hospices so there **is parity with funding for adult hospices**. Children and young people with life-limiting and life-threatening conditions in England, Northern Ireland and Wales deserve the same recognition, opportunity and support as those in Scotland.
4. 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.
5. 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.
6. 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.
7. 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 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.

8. 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%).
9. 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.
10. **We consider it pressing and urgent that the overall amount of funding available through the children's hospice grant reflects the increase in demand, costs and complexity of care needed by children and young people with life-limiting and life-threatening conditions. We recommend that the grant is increased in value to £25million per year. We base this on a 14% contribution to the current cost of the clinical care provided by children's hospices, which is equal to the contribution originally made by the Department of Health when the grant was first awarded in 2006/07. The uplift also recognises**
11. 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.
12. **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

13. 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.
14. 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

¹¹ Ibid.

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>

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.

- 15. 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)

16. 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
17. 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
18. 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.
19. 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.
- 20. 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.**

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/2q9nIWA>.

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

Ensuring nursing care today and tomorrow

21. Statutory and voluntary sector children's palliative care services require a sustainable nursing workforce.
22. Our research shows that 11% of nursing posts within voluntary sector children's palliative care providers are vacant – in line with the NHS average nursing vacancy rate (11%).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.
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.¹⁷
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 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.¹⁸ 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.¹⁹
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.²⁰ The Office of National Statistics estimates that there are 13,770,873 children aged 0-18 in England.²¹ If the RCN recommendation were to be met, this would therefore

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

¹⁷ 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>.

¹⁸ DH (2011). NHS at Home: Community Children's Nursing Services. P3. Available to download from <http://bit.ly/10zZtZV>.

¹⁹ Together for Short Lives (2016). Commissioning children's palliative care in England. Available to download from: <http://bit.ly/2iAOH3z>.

²⁰ RCN (2014). The future for community children's nursing: challenges and opportunities. P.10. Available to download from: <http://bit.ly/1QgLhZb>.

²¹ ONS (2016). Population Estimates Analysis Tool: Mid-2015. 'Persons UK' tab. Available to download from: <http://bit.ly/2iJOTgS>.

require approximately 5,508 community children's nurses. There are currently just 535 community children's nurses in England.²²

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

Preventing family breakdown

27. 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.²³
28. In Together for Short Lives' work with families, we regularly hear families say that caring for a child with a life-limiting condition can be isolating and, at times, very lonely. Families often say it's difficult to talk about their child's diagnosis with friends and acquaintances in their community because they don't understand what they are going through, or find it difficult to know what to say or how to react.
29. In our 2016 family survey, 84% of families caring for a child with a life-limiting or life-threatening condition said they have felt isolated and alone since their child's diagnosis. An even greater number (90%) said their relationships, social life and interactions with friends had been adversely impacted since their child's diagnosis. Parents need a break from providing 24/7 care to spend time with each other, with their other children or catching up with friends.
30. Research by the Local Government Association (LGA) has revealed that in 2015/16 councils overspent their children's social care budgets by a total of £605 million as they struggle to meet increased demand for children's services in the face of reduced government funding for local authorities.²⁴ The LGA found that three quarters of councils had exceeded their budgets in the past year and that councils will face a £2 billion shortfall for children's social care by 2020. **We ask that the government commits to carrying out an inquiry in to children's social care, as it has already committed to doing so for adult social care.**
31. **We support Children England's call to introduce a Children Act Funding Formula.** Protecting children from abuse and neglect is one of the most important responsibilities we have – as a society and as citizens in a democracy. It is the responsibility of central government to ensure our taxes are distributed fairly so that each area of the country can afford to meet the needs of its most vulnerable citizens who can have no wealth of their own – children. As Children England's briefing outlines, current government policy is leaving local authorities with a £2 billion funding shortfall for children's social care even whilst the number of children and families reaching crisis point is rising, and councils are struggling to fulfil their statutory duties to children in need.²⁵ With the Revenue Support

²² NHS Digital (2016). NHS Workforce Statistics - September 2016, Provisional statistics: Staff Group, Area and Level. Available to download from: <http://bit.ly/2j2srhm>.

²³ Steele R. (2000) Trajectory of certain death at an unknown time: children with neurodegenerative LTC illnesses. *Cancer Journal of Nursing Research* 32, 49-67.

²⁴ LGA (2017). Children's social care at breaking point, council leaders warn. Available at: <https://www.local.gov.uk/about/news/childrens-social-care-breaking-point-council-leaders-warn>

²⁵ Children England (2017). Don't take child protection for granted. Available at: <https://www.childrenengland.org.uk/dont-take-child-protection-for-granted>

Grant set to be cut off by 2020, councils must not be left to rely on the fluctuations of local business rate retention and council tax revenue to fund children's social care: it's simply not sustainable and puts children in the most deprived areas in danger of falling through a stretched-to-breaking safety net.

32. 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.²⁶ 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.
33. 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.
34. 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.²⁷ 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%.²⁸ 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.
35. 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.
36. **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.**

Lifting the baby benefit bar

37. 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.

²⁶ Together for Short Lives (2016). Commissioning children's palliative care in England. Available to download from: <http://bit.ly/2iAOH3z>.

²⁷ Department for Education (2010). Government announces £800 million to support families. Available at: <http://bit.ly/2kaaT55>.

²⁸ Every Disabled Child Matters (2015). Short Breaks in 2015: An uncertain future. Available to download from: <http://bit.ly/2iJ1p04>.

38. 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.
39. 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.
40. 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.
- 41. 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
2307	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'
135	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'
2442	England and Wales total
£58	Higher rate DLA mobility component for children
£141,636	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'
£7,365,072	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'

Care and compassion in bereavement

42. We welcome the government's announcement that it is to support a Private Members Bill to introduce a legal right to bereavement leave for parents whose child has died. The Bill, introduced to the House of Commons by Kevin Hollinrake MP, will seek to ensure that grieving parents in employment are guaranteed paid leave to grieve. This builds on the excellent work led by Will Quince MP, who began this campaign during the last parliament.
43. While we welcome this development, there are two aspects of this new benefit which we would like the government to clarify.
44. Parental leave payments such as the one proposed by the Bill can only be taken in multiples of one-week blocks. **We ask the government to work with colleagues at the Treasury to consider what can be done to enable Her Majesty's Revenue and Customs to offer more flexible, daily payments so that parent carers are not forced to take bereavement leave in one-week blocks.**
45. Self-employed people are not technically 'employees' and so are therefore outside the scope of this Bill. However, they will require the same amount of time and space to grieve following the death of their child and it is vital that they receive statutory support to do so. **We therefore ask the government to work with colleagues at the Department for Work and Pensions to make sure that a financial benefit equivalent to the payment provided for in the Bill can be offered to self-employed people who are bereaved of a child.**

For more information, please contact:

Shaun Walsh
Director of External Affairs
07506 211 765 shaun.walsh@togetherforshortlives.org.uk

James Cooper
Public Affairs and Policy Manager
0117 989 7863
0741 522 7731
james.cooper@togetherforshortlives.org.uk

Patrick McKenna
Public Affairs and Policy Officer
0117 989 7820
07964 470 879
patrick.mckenna@togetherforshortlives.org.uk