

A briefing from Together for Short Lives

Introduction

1. Together for Short Lives welcomes this bill and believes that it will introduce an important period of paid leave for parents to help them come to terms with the unbearable experience of losing a child. We welcome the government's support and thank Kevin Hollinrake MP for introducing it. We also thank Will Quince MP, who began the campaign to introduce this bill during the last parliament.
2. Together for Short Lives is the UK charity that, together with our members, speaks out for babies, 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.
3. Together for Short Lives has a range of resources to support parents of children with life limiting and life-threatening conditions from the point of diagnosis, throughout the child's life, death and beyond. Our [Family Companion](#) helps parents to get the care and support that they need, signposting you to the services, agencies and professionals that can provide support.
4. **We ask MPs to amend the bill by introducing a more flexible period of time in which parents can choose to take the leave (see paragraph 9 for more detail).**

Why the Bill is important

5. There are 49,000 children and young people across the UK with life limiting and life-threatening conditions. This number is growing, as medical advances improve yet policy and funding is not keeping pace.
6. Looking after a child 24/7 in the knowledge that they will die young places the heaviest emotional, financial and social pressures upon families. Securing statutory bereavement leave for families who lose a child is one small but important way in which that some of that pressure can be relieved and societal understanding and support improved. Coming to terms with a child's death is unbearable for parents, siblings and all the family.
7. In **Appendix one**, we provide a case study of one mother's experience of managing the death of her daughter and her job. **Appendix two** describes the financial pressures which bereaved parents face immediately following the death of their child, which can be even greater if the child had a life-limiting or life-threatening conditions.
8. There are many examples of employers showing fairness and compassion in the way they treat parents bereaved of a child; however, it should not be down to the discretion of individual employers as to whether parents should be allowed time off work to grieve for their child and make funeral arrangements.
9. Together for Short Lives, along with the National Bereavement Alliance, has pushed for the government to introduce this legal right to paid bereavement leave, as currently it is entirely at the discretion of employers as to whether parents are given time and space to grieve, as well as make funeral arrangements. We called for all parties to include parental bereavement leave in their manifestos for the general election 2017.

How we would like the Bill to be improved

The period of time in which parents are permitted to take their leave - line 26 of part 1 of the schedule (page two of the bill)

10. Although Together for Short Lives welcomes the bill, we ask MPs to amend line 26 of part 1 of the schedule (page two of the bill) to extend the leave period in which the leave must be taken from 56 days beginning with the date of the child's death to 52 weeks following the child's death.
11. Bereaved parents have told us that they would have valued flexibility in being able to decide when to take parental bereavement leave; the impact of losing a child affects parents in different ways and at different times:
 - Some parents will need time away from work immediately following their child's death to help them come to terms with what has happened.
 - Some will prefer to take time away from work to coincide with their child's funeral, which may not take place within two weeks of their death - particularly if this is in the winter months or if the funeral is delayed by an inquest.
 - Some may find that a significant date or anniversary during the course of the following year, such as the child's birthday, are the hardest periods of time to navigate.
12. While we appreciate that employers need to be able to plan and to know in advance when employees are likely to need to take leave from work, we note that there will be scenarios in which parents will need to take leave where their child's death is sudden or unexpected. In these circumstances, employers will have little or no time to plan for the bereavement leave which parents will need. As such, we believe that the potential impact of employers having to accommodate parental bereavement leave up to one year following the death of an employee's child as opposed to eight weeks will be a disproportionately small extra burden on them compared to the significant benefit that the added flexibility will give to bereaved parents.
13. We understand that employers find it easier to implement new workplace laws when they are based on similar precedents of statutory payments and periods of leave (such as paternity or maternity leave). We note that 52 weeks matches the period of time offered for maternity leave and as such is already recognised in statute.
14. We also note that extending the period in which parental leave can be taken will incur no additional expenditure for the government.

Eligibility for parental bereavement leave and payments

15. We do not believe leave should be restricted to parent carers, but also be available to legal guardians caring for the child, working grandparents, aunts and uncles who are significantly affected by the death.

Taking leave and payments in periods of time other than a week

16. Payments such as the one proposed by the bill can only be taken in multiples of one-week blocks. This is because of the payment systems operated by Her Majesty's Revenue and Customs (HMRC).
17. We ask that the minister speak to the Treasury to consider what can be done to enable HMRC to offer more flexible, daily payments so that parent carers are not forced to take bereavement leave in one-week blocks?

Extending leave and payment to self-employed people

18. Self-employed people are not technically 'employees' and are outside the scope of the bill.
19. We ask that the Bill be amended to make sure that a financial benefit equivalent to the payment provided for in this bill can be offered to self-employed people who are bereaved of a child?

The age of the child

20. As a result of advances in medical technology, many more young people with life-limiting conditions are living into adulthood.
21. We believe the Bill should be amended to ensure that parent carers who are bereaved of young people with life-limiting conditions up to the age of 25 should be able to access parental leave and payments.
22. There is a precedent for this age-range in another important piece of legislation, the Children and Families Act 2014. This is introducing a new special educational needs and disability (SEND) system in England for all children and young people with a special educational need and/or disability from birth to the age of 25.

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Appendix one: a bereaved mother's experience of managing her child's death and her job

In January 2013 I was on a 24 hour per week contract, working four days a week. My daughter was having investigations for a blood disorder, which involved weekly blood tests and hospital appointments. My work as a Family Support Worker involved short term interventions with families and home visits, so generally speaking I was able to fit my work around my family commitments with no disruption to my work.

My daughter had an emergency admission to the Oncology/Haematology Ward in February 2013 and I was able to take two days Carer's Leave. In April 2013 she was diagnosed with a life-threatening illness. I attempted to continue working but by early May it was clear that this arrangement wasn't working and I went off work on extended sick leave.

My manager telephoned me once a month and I always found her calls supportive and helpful. I was referred to Occupational Health, but because my daughter's treatment was in England (not Northern Ireland) I didn't get to Occupational Health until November 2013. My sick pay entitlement ran out in November 2013.

In December, I was summonsed to a formal meeting with my manager and HR team. I was told that I no longer had a legal entitlement to my job and that I needed to agree a date for returning to work or I risked my contract of employment being terminated. I agreed to a provisional date in January 2014, although I felt uneasy about this due to my daughter's medical condition.

My daughter was admitted to hospital in December 2013 and died in January 2014. My manager and all my work colleagues attended my daughter's wake and many also attended her funeral. They sent flowers, cards and other gifts.

I became really worried about losing my job as I love my work and I felt that mentally I needed to know that I had something to work towards. The chief executive of the organisation that I worked for sent a verbal message that if I needed anything that I was to come to them. My director also sent me a message of support. My manager informed me that with both of these senior officials on my side that I was to stop worrying about losing my job. My manager also sent me booklets and other appropriate literature regarding what to do when a child dies. She offered to help me source grief counselling through the counselling agency with which the Trust have a service level agreement.

I attended Occupational Health on a regular basis and found all the staff there kind and caring. My manager kept in regular contact with me. She came to the house for a face to face meeting around Easter time. By mutual agreement we decided that I would return to work 18.75hrs per week in September 2014, but because I had accrued so much annual leave I would be back on the payroll from July 2014.

The week before I returned to work, another manager contacted me to discuss my induction back to work. She advised me to book fewer home visits per day and to be gentle with myself. In 2015 and 2016 I was allowed to take less annual leave in the summer so that I could take three weeks annual leave at Christmas/New Year so as to be off for my daughter's birthday, and the anniversaries of her final admission to hospital, her death and burial. In 2015 my manager said to me when I was going off that if I needed more time than that, to just take some sick leave. In actual fact I have never had one day of sickness absence since my daughter died. I am now on a 30 hour per week contract. Occasionally I will still have a 'bad day' at work and my colleagues are supportive and understanding. They know that on my good days I give 110% so they give me space to grieve and are gentle with me when I need it.

Due to a recent internal reorganisation I was supposed to change my work base but this coincided with a difficult time for me emotionally. When this was explained to my manager she agreed to delay my move, although I will gradually phase in my new duties while working from my current

base, which is acceptable to both my manager and I. Working in such a flexible, supportive and understanding environment really helps me as a bereaved parent.

Appendix two: Financial pressures for families following a child's death

1. Corden et al. found that, for parents, 'the period immediately following the death of their child is one in which they face significant financial problems, with serious implications for the healing and adjustment process on which the surviving family must embark'¹.
2. Most families suffer from an immediate loss of income after the death of their child due to the cessation of benefits including Carer's Allowance, Disability Living Allowance, and Child Benefit. This causes difficulties for families as they usually have a 'debt legacy' from the costs of caring for their child.
3. Interviews with families who use Martin House Children's Hospice found that families owed money to a 'variety of creditors, including fuel boards, banks, commercial credit companies, building societies, retail outlets, garages, travel and holiday firms, relatives and friends. Some bereaved families were believed to be in danger of repossession of their home as a result of mortgage arrears'

¹ <http://www.york.ac.uk/inst/spru/research/pdf/Financial.pdf>