

MP Briefing for Parental Bereavement (Leave and Pay) Bill Second Reading Debate

Friday 20 October 2017

About Rainbow Trust

Rainbow Trust Children's Charity provides support for families whose child is diagnosed with a life threatening or terminal illness. Through nine teams of Family Support Workers, we provide emotional and practical support to more than 2,300 families each year, across England. Family Support Workers support the whole family in the place of the family's choice, providing a bespoke service according to the family's needs.

In 2015-16 there were 67 families supported by Rainbow Trust whose child died during the year. A strength of our service is that while a lot of professionals involved in a child's clinical care will cease contact with a family after a child's death, Rainbow Trust support can continue with the same member of staff available as and when requested. Some parents value a person to talk through their worries about returning to work.

About the bill

We welcome this Bill as a major step forward in ensuring all employed parents will have a statutory right to paid bereavement leave in the event of a child's death. This would remove the need to negotiate time off at a hugely stressful time for parents.

In situations where a child has had a life threatening or terminal illness, working parents may have spent months or even years negotiating with their employer to take periods of time off work to support their child at times of medical crises or in patient treatment, and may feel they have exhausted their employer's goodwill well before the point of their child's death.

We also welcome that the Bill does not require parents to take their leave immediately after a child's death, but provides a window in which the leave can be taken

Proposed amendment

We recommend that the window of opportunity to start the leave be extended from eight weeks (56 days) to 52 weeks. This would give parents more flexibility to take the leave when they need it most. This could be around a particular date, such as the child's birthday, or the anniversary of their death, or at another time when the family is particularly struggling to come to terms with their loss.

The specific window will be set out in Regulations, but the Bill sets out the provisions that those regulations must contain.

We would like to propose the following change:

Page 2, Line 26 replace '56 days' with '52 weeks'

Additional comments

We appreciate that there is limited time for this Bill, and for this reason we are only suggesting one amendment.

However, we would value the following issues being raised in the debate:

- a. While we recognise that this Bill has limited time in which to be passed, Rainbow Trust is concerned that legal guardians, such as foster carers, should receive an entitlement. We have experience of supporting foster carers who have been primary carers of a terminally ill child.

We would also emphasise that the wider family can be deeply affected, including working grandparents, aunts and uncles. Rainbow Trust therefore hope that future measures might look at the needs of adults other than a parent to be eligible for paid bereavement leave if they have been closely involved in a child's life.

Please ask the Minister if she would consider reviewing the impact of the Bill on employees and employers after a year, and consult on the wider circumstances of bereavement, in which statutory provision of leave and pay would be appropriate.

- b. Many families we support include self-employed people, or those on those on short term or zero hours' contracts which would not enable them to qualify for the leave and pay that this bill provides.

Please could the Minister set out what plans there are to ensure future provision for these groups.

- c. As a result of the Children and Families Act 2014, the Special Educational Needs and Disability (SEND) system in England recognises the needs of young people between the ages of 18 and 25. Some parents we are in contact with feel very strongly that the loss of a child above 18 is no less traumatic than a child aged 17 or younger.

One parent has said:

'I hope that the Bill for bereaved parents that you mentioned does include parents of children over 18. It should also include grandparents. The impact on the whole family is catastrophic, and on friends, partners also. Time and time again, I have found out about initiatives on this journey, and many of them, sadly, would not have impacted on our daughter nor us.'

Please ask the Minister if she might consider extending the provision of this Bill to support parents bereaved of an 18-25 year old.

Appendix 1

Rainbow Trust 2014 survey of bereaved parents about bereavement and work

In 2014, Rainbow Trust conducted a small survey of bereaved parents, which received 68 responses. Of these, 55 respondents had been working at the time of their child's death, 11 had not been working, and two had been claiming benefits.

Findings included:

- More than half of the parents who were working at the time when their child died did not feel they were given enough time to cope
- 50 per cent took at least one month off work
- More than one in three felt that four months or more off work would be ideal
- 58 per cent of respondents felt employers were supportive, while 27 per cent felt they were initially supportive, but it did not last. Nine per cent felt employers were not at all supportive
- One in three bereaved parents felt that their employers put pressure on them to come back to work after the death of their child
- 10 respondents left their job because of the way they were dealt with during their bereavement – whether they resigned, lost their job, or were made redundant.

Appendix 2

Family experiences

The following examples of returning to work after child bereavement were gathered in August 2017, either through direct contact with a bereaved family, or through the Rainbow Trust Family Support Worker who is in regular contact with them.

Family A

This family is supported by Rainbow Trust and was bereaved in 2017:

- The father took ten days' leave which his employer provided as paid leave for the death of a child or spouse. They understood that this was at the discretion of the employer. This was taken as one block and the mother was unsure if there was potential to take this in more than one block. The mother reported that if this had been unpaid it would probably not have been a barrier to taking the leave
- The mother commented that what parents most want from an employer is flexibility and understanding. Her husband's employer was flexible regarding return to work, and her husband was able to work from home for a week when he returned to work.

'The employers were very supportive and told my partner that if there was any morning that he couldn't face work, or needed to work from home, then to just let them know.'

I think the approach an employer takes to bereavement leave is crucial in helping bereaved parents try and continue with normal life.

If the bereavement policy is not flexible, and if the employers are not understanding of the catastrophic avalanche of feelings that accompany losing a child, then remaining employed or performing well in your role could be extremely difficult.

More needs to be done to ensure employment law reflects this and that there is a minimum requirement of days for bereavement leave put in place.'

Family B

This family is supported by Rainbow Trust and was bereaved more than a year ago:

- Both parents have voiced that their employers were very supportive towards the end of their daughter's life and in the immediate months after their daughter died
- However, the parents faced challenges when returning to work. They felt that colleagues expected them to have got over their loss, and that their employers were less sensitive towards them than they were at an earlier stage
- Both parents have expressed that they have both good and bad days in their work environment, but that they are finding the second year of losing their child is harder than the first. In the words of their Family Support Worker, '*reality sets in that their daughter is not going to be around anymore.*'

Family C

The family's daughter was 21 years old at point of diagnosis. She died aged 22 in 2008 after ten months of treatment for cancer. Rainbow Trust did not support this family, but the mother is active in a local parent's voices group, and wished to share her experience:

- The mother described her experience with her employer as positive which she attributes mainly to '*an understanding boss.*' She is an academic senior lecturer in mental health. The father was employed in the civil service at the time of their daughter's illness
- The family's finances, and the uncertainty as to their daughter's prognosis, meant that both parents decided to stay in their work. The mother says she wanted to give up her work and knew this would have been an easier option, but her daughter was keen she did not make this sacrifice, and her employer was also keen to make adjustments to enable her to work flexibly. Moreover, the family were concerned about losing their house as they had had some financial problems a few years earlier. As a student who intended to return to her studies, their daughter was not entitled to any benefits in her own right
- The mother reports that her line manager was very understanding and encouraged her to only go into work for essential hours like lectures, and then to do all other work in her own time. This meant she could spend eight hours a day at her daughter's bedside in hospital during the ten months she was ill. She worked her hours around these visits. Her husband visited at different times of day to maximise company for their daughter. The mother comments that continuing to work did provide her with some normality which was beneficial
- Following their daughter's death, the mother took five months of sick leave on full pay, signed off by her GP. Her husband had a positive experience from his employers, but needed to take time off for an injury which had been aggravated because of frequently walking to hospital, and this took longer to heal than expected. He felt the external outsourced assessors used to verify his sick leave were lacking in empathy as to how bereavement could be contributing to his physical health.
- The mother reports that she did not want to return to work as she felt '*numb*'. She was also unhappy that her return, when it came, was not staggered. However, she feels that getting up every day was very positive and gave her purpose. She feels long-term loyalty to her employer as a result of their flexibility, and she is confident this makes her more productive. To remember her daughter, she always takes a day of leave to mark her birthday, and the day of her death
- This family draw attention to the long-term impact of bereavement. The mother comments that she is not '*firing on all cylinders*' and she feels that people do not consider the long-term impact. She is aware of some bereaved parents, whom she has met through parent networks, who still cannot function well and who remain out of work.

Family D

This family has been supported by Rainbow Trust since their daughter was diagnosed with cancer in 2013. Their daughter died in 2015, and the parents and younger sibling continue to receive bereavement support from Rainbow Trust:

- The mother felt fortunate that her employer, a regulatory body, was compassionate in its approach. She comments, *'I feel I have been extremely lucky.'* Following her daughter's diagnosis, the mother was off work unpaid for two years, while she became her main carer
- She never felt any pressure from her employer to return to work and she felt fortunate that her job was kept open. When she returned to her post, it was on a phased return
- She has two line managers, and says, *'they have only provided me with the utmost support and that has continued. I received a warm welcome from my colleagues when I returned, many whom I have worked with for a number of years'*
- The mother has since needed to take additional time off for her own medical treatment, but she continues to feel supported by her employer.

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