

# Consultation Response

Response to the Department for Business,  
Innovation, Science and Trade's consultation on  
employment rights for unpaid carers and parents  
of seriously ill children

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## 1. Introduction

The Children's Commissioner is a statutory position created by the Children Act 2004. The Commissioner's remit is to promote and protect children's rights in accordance with the United Nations Convention on the Rights of the Child.

In the Commissioner's role, she has met and heard from parents of children with serious, and sometimes life limiting health conditions. Some of these parents have experienced high levels of often preventable stress and hardship because of inflexible working conditions, which has meant they have either left their jobs to care for their children or they are struggling to hold down work. Precarity in their parent's employment has a significant effect on children whose wellbeing is intimately connected with their families.

In her recent report, 'Children waiting to leave hospital' about children experiencing delayed discharge and prolonged hospital stays, the Children's Commissioner found that within one generation of children born in or after 2007, 260,141 children spent over three weeks in hospital. Over a thousand (1,342) children spent over a year in hospital over their childhoods. Long hospital stays disproportionately affect children living in more deprived areas, and children from ethnic minority backgrounds. In conversations with parents and professionals, they detailed the financial consequences, including poverty, of long and recurrent hospital stays endured by seriously ill children.<sup>1</sup>

This consultation seeks answers on how the proposed changes to carer's leave and a new form of leave for parents of seriously ill children will impact employees with caring responsibilities and their employers. The office's response sets out the positive impact the proposals will have specifically on parents with caring responsibilities for a child who is seriously ill and / or disabled. However, these proposals will also have a significant impact on individuals who need care from their loved ones – and notably for this office's response – children growing up with disabilities and health conditions. These children may experience difficulty and pain because of their disability or health condition, be admitted to hospital, have time out of school and away from friends. And while children's complex needs can unavoidably alter aspects of their childhood, it should never change the fundamentals of quality of life: Children should not miss out on is the love and care of their parents who are facing decisions between earning a living and caring for their child with complex needs; they should not face poverty and precarity

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as a result of inflexible working conditions; and they should not ever be made to feel like the financial challenges their families face are because of their parents' caring responsibilities. Although this group is not considered within the consultation's questions, how children will be affected by any changes made by the Department should be a key factor.

The steps being proposed by the Department for Business, Innovation, Science and Trade are welcome. Focusing on how carers can be better supported to stay in employment, providing stability for their families, is something the Children's Commissioner called for in the report. It is a step forward in better supporting families, and children growing up with disabilities and health conditions that mean they need additional care. Looking ahead, more must be done across government, in particular in the NHS and children's social care, to provide children with complex needs with more support, and a better quality of life.

## **2. Carer's Leave**

**From your perspective, how effective are existing employment rights at helping unpaid carers balance work and care?**

Quite ineffective

**In what circumstance should unpaid carers be able to take carer's leave entitlements?**

- To provide personal and emotional support
  - To provide practical support (for example cleaning, gardening, paying bills)
  - To help with official or financial matters
  - To provide personal and/or medical care (for example washing, dressing, administering medicine)
  - To make arrangements for the provision of care
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- To accompany people to appointments
- To allow the carer to rest and recuperate, take up carer support, and/or maintain their health and wellbeing

### **From your perspective, who should a carer be able to take carer's leave entitlements to support?**

- A spouse or civil partner
- A child
- A parent
- Any person who lives in the same household as the employee (otherwise than by reason of being their employee, tenant, lodger, or boarder)

### **Would extending the existing unpaid carer's leave entitlement be helpful for carer's balancing work and care?**

Very helpful

### **If the current entitlement of up to 5 days unpaid leave was to be extended, how many days of unpaid leave a year would be appropriate?**

10 days

### **From your perspective, what would be the impact of extending unpaid carer's leave on employees with caring responsibilities?**

When looking at how an extension to unpaid carer's leave could improve the lives of families who have children who are seriously unwell and / or disabled – allowing a parent to take unpaid leave over the year provides additional flexibility when there are sudden changes in caring responsibilities, including a

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hospital admission, an escalation in behaviour or a bad infection. This would enable parents who are working and managing care responsibilities alongside this to take a period of short term leave because of unavoidable, and unpredictable circumstances – including providing end of life care to their seriously ill child.

As covered under the question on the impact of paid carer's leave, this leave would be more impactful if carers were remunerated and enable to carry out their additional responsibilities without financial punishment.

## **2. A right to return**

**Would a longer period away from work with a 'right to return' be helpful in supporting carers to balance work and care?**

Very helpful

**If a 'right to return' were to be introduced, who should be eligible?**

All unpaid carers, including those providing end of life care and parents or primary care givers providing care for seriously ill children

**If a 'right to return' were to be introduced, what form of evidence should employees have to provide to prove their eligibility?**

Certification from a relevant professional

**How long would be appropriate for an extended period of leave with a 'right to return'?**

10 – 12 months

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## **In your view, what would be the impact of having access to a 'right to return' on employees with caring responsibilities**

When looking at an approach that would work for parents and legal carers when their child has a serious illness and / or disability, having a 'right to return' that allows a child's parent to take a period of time of during an acute, and enduring phase of their child's illness would provide a form of security and hope for families. This includes families who are providing palliative or end of life care to their seriously ill child, where children's health and needs and the timing of end of life care can be changeable and require extensive time away from work.

For some families, their child will be seriously ill for extended periods of time. They may not know the extent of their caring responsibilities, or be uncertain about the progression of their child's illness, and having an option that enables them to take leave from work but secures a future return would provide families with stability, and allow parents to go back to work when they are able to.

### **3. Paid carer's leave**

#### **Would the introduction of a statutory paid carer's leave entitlement be helpful in supporting carers to balance work and care?**

Very helpful

#### **If paid carer's leave was introduced, what evidence should employees have to provide to prove their eligibility for it?**

Certification from a relevant professional

#### **How long would be appropriate and reasonable for a potential paid leave entitlement?**

Over 5 days

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## **If paid carer's leave was introduced what baseline level of remuneration would be appropriate for those taking**

90% pay

## **From your perspective, what would be the impact of introducing paid carer's leave on employees with caring responsibilities?**

For parents caring for a child who is seriously ill or disabled, having a form of paid leave for when their child is experiencing an escalation in their needs could allow the parent(s) to stay in work long term. Many of these parents will be caring for children with life long needs, who will experience an escalation in those needs. Having a way to stay in work but take a form of short-term, paid leave as needed during the periods when their child's needs escalate is a measure that would ensure families are not worse off, or thrown into uncertainty when experiencing more challenging circumstances.

This could and should work in addition to a form of paid leave for parents in the initial period after their child has become seriously ill. For parents who take this leave and return to work, their child may continue to be unwell in the long term. These families will still need to provide care and take on greater responsibilities when their child's needs escalate.

Paid carer's leave must also be available for parents providing end of life care to their seriously ill child – who should not be punished financially for being part of such a critical moment of their child's life.

## **4. Focus on government interventions**

### **In your view, what should the main government focus be for any immediate action following the review?**

Choice: Reducing the risk of carers leaving work due to caring responsibilities

Explanation:

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The steps being proposed by DBIST are welcome, but are one part of a what government can and should do to better support children with complex needs and their families. There needs to a cross-government focus on the support given to children and their families when a child has a serious illness and / or disability.

Paid carer's leave, a right to return and paid parental leave will help many families. But there is insufficient support from children's social care or the NHS for too many children with complex needs requiring round the clock care. This means, for many parents, caring responsibilities are so significant that returning to work may be impossible.

A lack of support for a child with complex medical needs and / or disabilities, for example lack of care worker or nursing care or not having a school place can also lead to parents leaving work is not a challenge that can be overcome by short-term paid leave or unpaid leave with a right to return. Coordinated, consistent and well-resourced support from children's social care and the NHS is needed to enable parents to provide intensive, complex care to their child sustainably – not least in the instance that a child spends longer in hospital than they need to because of huge challenges across the health and social care system.

## **In your view, which, if any, of the approaches discussed in Chapters 1 and 2 would best address this focus and why?**

The proposed changes to carer's leave – including extending it, introducing a form of paid leave, and allowing carers a right of return – are the right approaches to providing additional flexibility to carers and their children. By providing a form of improved leave that allows parents of children with serious disabilities and / or illnesses to step away from work during a crisis or escalation in their child's needs, as well as a right to return to bridge an extended period in children's lives when their parents need to be there for them are the right methods to support families with such varied circumstances and demands on them.

**From your perspective, which potential approach might best help employers and carers balance work and care?**

When looking at an approach that would work for parents and legal carers when their child has a serious illness and / or disability: The most vital part of better supporting families is introducing paid carer's leave, a right to return for carers and paid leave for parents in the aftermath of their child becoming seriously ill. Extending unpaid carer's leave is welcome, but still leave families worse off because of unavoidable changes in caring responsibilities.

## **5. Employment rights for parents of seriously ill children (Hugh's Law)**

**How aware are you of the support currently available to parents of seriously ill children?**

Very aware

**Would the introduction of a paid leave entitlement for parents of seriously ill children help parents in this situation?**

Very helpful

**If paid leave for parents of seriously ill children was introduced, what form of evidence should employees have to provide their eligibility?**

Certification from a relevant professional

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**If it were introduced, how long would be appropriate and reasonable for a one off paid leave entitlement per child?**

9 - 12 weeks (12 weeks being the preferred option)

**If paid leave for parents of seriously ill children was introduced, what should be the baseline level of remuneration for those taking it?**

90% of pay

**Which of the following approaches to support parents of seriously ill children would be most helpful to parents, their families and employers?**

A shorter, paid period of time away from work to provide financial support in the immediate aftermath

**From your perspective, what would be the impact of introducing paid leave for parents of seriously ill children on parents in this situation?**

For parents and legal carers of a child who is seriously ill or disabled, a form of paid leave that enables them to care and spend time with their child following a diagnosis or crisis in their health is essential. Whether a child has been diagnosed with cancer, has acquired a brain injury, has developed complex medical needs or has a serious mental health condition requiring hospitalisation or intensive outpatient support – they will need their primary carers to be with them throughout.

This includes parents caring for their child in hospital. In the Children's Commissioner's office report, *Children waiting to leave hospital*, newly published data on children's lengths of stay in hospital show that a minority, but still a significant minority, of children spend long periods of time in hospital over their lifetimes.<sup>2</sup> This proposal of paid leave from the Department for Business, Innovation, Science and Trade responds to this clear need for paid leave from employment for these children's parents, many of whom will be by their children's sides throughout:

- In one generation of children<sup>1</sup> (11,768,668 in total), the office found that, on average, children spend only 3.5 days in hospital over their childhoods – and this accounts for most children being born in hospital.
- Some children, however, spend much longer. Of 11,768,668, 260,141 children spend three weeks or more in hospital over their childhoods, 34,846 spend over three months, and 1,342 spend over a year. Most of these children will have parents who are providing care in hospital, including practical and emotional care, while children are experiencing pain, trauma and uncertainty.
- More than double the proportion of children from the most deprived backgrounds are spending more than three weeks in hospital compared to the least deprived children. This disparity could be the result of a number of factors, including entrenched health inequalities. While these inequalities will take time to tackle – a form of paid parental leave for parents will help to prevent these families experiencing further disadvantage by losing their income while their child is in hospital and unwell.

The office heard from parents about the immense difficulty they faced financially because of their child being in hospital. Due to her child's long stay in hospital (and wait to be discharged), and in anticipation of caring for her at home, one parent explained:

*"I've had to quit my job, well, I haven't just yet, I'm still technically I'm sick, but next month when my sick note runs out I will be quitting my job, so I'm losing a lot of money, so it's, yeah, it's really hard. It's really hard"* – Mother of 5 year old

For two families whose babies were in hospital, the newly introduced Neo-Natal Leave had significantly helped, indicating how paid leave for parents of a seriously unwell child can have an impact,

*"Neonatal care leave policy came in April, so we were both able to take advantage of that and both our workplaces paid us in full for the 12 weeks. ... So we recognise that we have been very lucky. But*

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<sup>1</sup> Using the Children's Commissioner's powers under the Children Act 2004, the office acquired data from NHS Hospital Episode Statistics (HES) dataset. The office asked the HES team for details of hospital stays for children who, on 30th November 2024, were children (aged 0 to 17), including children born in hospital and children who spent time in hospital who had very sadly died.

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*obviously if she wasn't a baby, if she was an older patient that had to be here, then suddenly that's not there anymore. I don't really see why it's any different" - Mother of baby*

Having paid leave for parents of seriously ill children along with an option to take an extended period of leave with a right to return, or short term paid carer's leave would help families whose child has long term, complex needs that fluctuate, requiring repeated hospital admissions. As one parent told us, these periods of time where their child was hospitalised had led to job insecurity,

*"[partner] struggled then to get into some at full time because we were in and out in and out hospital. So that impacted on our employment. Yeah. Yeah, a lot" – Bereaved mother*

While caring for a child in hospital, living costs can be higher. The cost of being in hospital includes food, toiletries, phone bills (when Wi-Fi access is poor), washing clothes (children tend to get through more clothes when ill), parking and petrol (travelling long distances between home and hospital). Schemes to support families by provided free or discounted food are inconsistent across the country. The government covers travel costs to hospital for parents whose child has cancer, but not other serious illnesses that hospitalised children can have.

*"It's those little things that do add up and you've still got to pay your bills at home to keep your house."*  
– Mother of 7-year-old

Being out of work during a period of high expenditure is impossible for many families – who try to manage work and care of their child, putting them under huge stress:

*"Finances are a massive stress for families particularly when they're out of area... Some travel like 40 miles each way and it can be an hour and a half. And then petrol. So we've got a family at the minute whose dad's going to work. [They] live in [town], so he drives back for midnight to come back and then goes back to work the next day ... I'm really worried about him driving [while tired] and making sure that he's eating and drinking, and that impact it's having on that family" - Child Psychologist*

## References

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<sup>1</sup> Children's Commissioner's office, Children waiting to leave hospital, [Link](#)

<sup>2</sup> Children's Commissioner's office, Children waiting to leave hospital, [Link](#)



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