



Carer's Leave - response form

The consultation is available at: www.gov.uk/government/consultations/carers-leave

Questions

Organisation: Rainbow Trust Children's Charity

Address: Cassini Court, Randalls Way, Leatherhead, Surrey KT22 7TW

	Respondent type
<input type="checkbox"/>	Business representative organisation/trade body
<input type="checkbox"/>	Central government
<input checked="" type="checkbox"/>	Charity or social enterprise
<input type="checkbox"/>	Individual
<input type="checkbox"/>	Large business (over 250 staff)
<input type="checkbox"/>	Legal representative
<input type="checkbox"/>	Local government
<input type="checkbox"/>	Medium business (50 to 250 staff)
<input type="checkbox"/>	Micro business (up to 9 staff)
<input type="checkbox"/>	Small business (10 to 49 staff)
<input type="checkbox"/>	Trade union or staff association
<input type="checkbox"/>	Other (please describe)

	If you are an employer, how would you classify your organisation?
<input type="checkbox"/>	Private sector
<input type="checkbox"/>	Public sector
<input checked="" type="checkbox"/>	Charity/Voluntary sector
<input type="checkbox"/>	Other (please specify)

	If you are an individual, are you:
<input type="checkbox"/>	Employed
<input type="checkbox"/>	Self-employed
<input type="checkbox"/>	Unemployed
<input type="checkbox"/>	Retired
<input type="checkbox"/>	Not looking for work
<input type="checkbox"/>	Other

Existing employment rights and practices

Question 1 Have you or your employees used any of the below options to take time out of work to fulfil caring responsibilities? Please select all that apply.

- Yes, annual leave
- Yes, formal flexible working (meaning a change to contracted hours or location of work)
- Yes, time off for dependants (the statutory right to leave in emergencies)
- Yes, unpaid parental leave
- Yes, informal flexible working (such as an afternoon or morning off or occasional homeworking)
- Yes, other (such as special/compassionate leave granted by the employer)

No

Please comment on your experience of these existing rights and practices in relation to care, including what specific caring needs the leave was used for:

Rainbow Trust understands that employees who balance their work and home responsibilities effectively are more engaged and productive. It is committed to providing a successful Work Life Balance approach, which complements business benefit with individual well-being.

Supporting the family unit is at the heart of the service Rainbow Trust provides – this principle is extended to its employees for all aspects are caring responsibilities, e.g. allowing time to be with a relative at end of life.

Who would be eligible to take Carer's Leave?

Question 2: Do you agree that an employee should be able to take Carer's Leave to provide care for a dependant such as a spouse or civil partner; a child; a parent; a person who lives in the same household as the employee (other than as an employee, tenant, lodger or boarder); someone else who reasonably relies on the employee for care?

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree Don't know

Please provide reasons for your answer: The creation of an entitlement to Carer's Leave, separate to existing employment rights, would be one step to help to address the burdens on employed people who provide care for another person in some form. Rainbow Trust Children's Charity provides emotional and practical support for families caring for a child with a life-threatening or terminal condition. We strongly support the creation of Carer's Leave to allow an employee to care for a dependent and in particular for a child with a life-threatening or terminal condition. Such parents will be under significant strain owing to the practical and emotional demands of their situation, which may include attending frequent medical appointments, visiting their child during periods of in-patient treatment, monitoring medical equipment or administering medicine throughout the day and overnight. In addition there may be healthy siblings to care for alongside this. In our experience, in two parent households, one parent often becomes the sole breadwinner. This parent will have less involvement in their child's care during working hours although they may well assist with care before and after work. By creating this entitlement, employees may feel less guilty about their dual roles, and may, we hope, be treated more compassionately by colleagues and managers throughout the year. A mother whose husband needed to take time off for each of his son's three rounds of chemotherapy commented: 'One thing as parents we would like from employers is the understanding that this is the most difficult situation for anyone to go through.' Rainbow Trust is also aware of families where grandparents are closely involved in their child's care, for instance. For these reasons, Rainbow Trust supports the suggested definition of who would be entitled to take the leave because it is sufficiently flexible to cover a range of circumstances and situations by including 'someone else who reasonably relies on the employee for care'. This would provide consistency to employers and would the entitlement to a range of

relatives such as a grandparent, aunt or uncle, or adult sibling if they are depended upon to care for a child or young person with a life- threatening or terminal illness, as well as foster and adoptive parents.

Question 3: Are there other caring relationships that you think should be considered for inclusion within the scope of Carer's Leave? Comments: As stated in our answer to question 2, we feel the suggested definition offered is suitably broad to encompass a range of different caring relationships.

Question 4: Which conditions on care need do you believe are appropriate for Carer's Leave? Please select all which apply.

Length of the condition. Comment on appropriate length: We do not believe setting a length would be appropriate – see our comments under 'Other'

X Conditions which automatically qualify as a disability under the Equality Act 2010 (Cancer, HIV and MS). Comments: We agree that these conditions would be a suitable qualification.

X Terminal illness. Comments: We agree that a terminal illness should qualify as a relevant care need but would highlight this can be difficult for a clinician to judge.

X Other. Comments: We do not believe that a length of time for a condition should be specified because there can be uncertainty as to whether or not a child's condition is life-threatening or terminal, and how long a period of serious illness may last. While we understand the desire to distinguish between ongoing needs and temporary crises, it would be difficult to set a minimum time that the person being cared for has a condition. A baby or child's diagnosis with a life-threatening illness may be sudden, and the course of illness may be unpredictable. There are also a growing number of children who have serious but undiagnosed conditions for whom this uncertainty is particularly stark. Therefore the length of a condition may be unknown at the point that the parent or relative applies to take Carer's Leave. Restricting the care need to where it is likely to last for six months or longer may create challenges in instances where clinicians feel unable to predict confidently the course of an illness. This may be a particular problem as regards seriously ill babies under one. Some can move from being gravely ill in intensive care to making a full recovery, while others may be recognised over time as having a permanent condition which is likely to shorten their lives. This is the age group within 0-19 year olds with the highest prevalence of life-limiting and life-threatening conditions according to the most recent academic analysis (*Make Every Child Count*, Fraser, Gibson-Smith, Jarvis, Norman, Parslow, University of York, 2020). Furthermore, our understanding is that most employers who offer carers' leave at present do not collect detailed information on who needs care and how long the condition will last, and we therefore suggest that any definition is sufficiently flexible to encompass a range of situations.

Question 5: If you do not believe that any conditions about care need are appropriate, please explain why and comment on any other conditions which might be appropriate: [Click here to enter text.](#)

Question 6: Which qualifying period do you believe is appropriate for Carer's Leave. Please select one option.

6 months of continuous employment with their employer

3 months of continuous employment with their employer

A day one right (no qualifying period, but with appropriate notice period)

Other, please specify [Click here to enter text.](#)

Please provide reasons for your answer: Carers wanting to return to work or move jobs say that a barrier to doing so can be not knowing how 'carer friendly' their future employer might be. Creating the entitlement as a day one right would prevent carers' employment and career being damaged by their responsibilities. It is also important to recognise that caring is unpredictable and requiring a period of employment before acquiring the right to Carer's Leave might mean that some employees are unable to use it when it is most needed. At the same time, if an employee feels they must leave their role in the first six months of employment because of the caring needs of a dependent, this is undesirable and costly for the employer. It is our understanding that most employers who offer Carer's Leave already do not specify a time period for an employee to qualify for it.

What the leave can be taken for

Question 7: Do you agree with the proposed reasons for taking Carer's Leave?

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree Don't know

Please comment, including on whether Carer's Leave should be available to use to accompany someone to appointments: Rainbow Trust would support the ability of using Carers Leave to accompany someone to appointments. Seriously ill children may have contact with up to 30 different professionals and appointments may occur throughout the working week. Indeed, some families tell us that Carer's Leave would be useful to them specifically because of the need for two parents to attend occasional appointments with their child at some distance from the family home (e.g. 1-2 hours travel time) or appointments which are especially serious for their child (e.g. hearing the outcome of a test). We see no distinction between using the leave for attending appointments or any of the other reasons listed in the consultation document.

Question 8: Are there any other reasons that you think should be included?

[Click here to enter text.](#)

What the leave cannot be taken for

Question 9: Do you agree that childcare (other than where the child has a disability or other longer-term care need) should be out of scope for Carer's Leave?

Strongly agree **Agree** Neither agree nor disagree Disagree Strongly disagree Don't know

Please provide reasons for your answer: Given the range of existing employment rights we do not consider there is a need to include childcare in the proposed entitlement.

Question 10. Do you agree that caring for a person with short-term care needs should be out of scope for Carer's Leave?

Strongly agree Agree Neither agree nor disagree **Disagree** Strongly disagree Don't know

Please provide reasons for your answer: As set out above, in some instances the nature of serious illness in childhood can make it hard to determine whether a baby, child or young person's needs are short or long term. Recent academic research by York University (*Make Every Child Count*, Fraser, Gibson-Smith, Jarvis, Norman, Parslow, 2020) showed that there has been an increase in prevalence of life-limiting and life-threatening conditions across all age groups of children between 2002 and 2018. Prevalence was highest in the under ones, and we know that a baby's serious condition can move quickly between a life-threatening and stable condition. We would encourage BEIS to recognise that judging whether a need is short-term or long term may be difficult for clinicians.

Question 11: Are there any other circumstances or activities which Carer's Leave should not be taken for?

[Click here to enter text.](#)

Evidence

Question 12. Do you agree that an employee should in the first instance be able to self-certify their eligibility for Carer's Leave?

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree Don't know

Please provide reasons for your answers: We strongly agree that employees should self-certify for Carer's Leave. This is a light touch and reasonable approach. With regard to information about for whom they are providing care, or what the care need is, we suggest that carers should only sign a general statement in order to guard the personal data of the person being cared for.

Question 13: If you strongly agree or agree, how often do you think an employee should self-certify their eligibility for Carer's Leave?

Each time they request the leave Once per year Other, please comment: [Click here to enter text.](#)

Please provide reasons for your answers: We feel that self-certifying at the point of requesting the leave would make sense because the situation of the person they are caring for may change from year to year.

Question 14: Do you agree that an employer should be able to request further evidence if they are not satisfied with the self-certification?

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree Don't know

Please provide reasons for your answers

The request for additional evidence could helpfully be aligned to similar provisions in the right to 'time off for dependants'. This provides consistency between different provisions.

Question 15: If agree or strongly agree, please describe what evidence could be provided to demonstrate:

- The need for care (of the person being cared for): As with requesting 'time off for dependants', we believe that the exact type of evidence should not be specified. We would envisage it being a small minority of cases where it may be reasonable for employers to request further evidence.
- What activities the leave is used for: As with requesting 'time off for dependants', we believe that the exact type of evidence should not be specified. We would envisage it being a small minority of cases where it may be reasonable for employers to request further evidence.

Question 16: Please comment on the key difficulties or challenges associated with providing and appropriately handling evidence, including data protection issues related to information about a person's health:

With regard to parents or relatives seeking time off to care for a seriously ill or disabled child, a child's personal data has particular protection under the GDPR. Children aged 13 or over without a learning disability would need to provide their own consent for their data to be shared. Those providing evidence related to the care of children under this age would need to show consent from whoever holds parental responsibility for them, e.g. a grandparent would need to evidence consent from a parent if seeking to take Carer's Leave. In terms of the type of evidence, receipt of Disability Living Allowance (DLA) could be one form of evidence, but we know not all families would receive this – for instance, if their child was suddenly diagnosed with cancer and was undergoing immediate and intensive treatment, a parent is unlikely to prioritise applying for DLA in the first instance. Those providing care who do not live in the family home may also find it more time-consuming to access letters and information relating to the person's health, appointments or care needs.

How the leave can be taken

Question 17: Please comment on the pros and cons for employees and employers, if the leave was available to take as:

A week of unpaid leave, available to take as a single block?

Pros for employees: Unclear if any advantages

Cons for employees: Less flexibility to take leave in accordance with the needs of the person that they care for. Potential for far fewer employees to take the leave in light of the greater amount of lost household income. It is well documented that households where a child is seriously ill will have a number of additional costs incurred in relation to care (such as cost of hospital car parking, petrol to attend treatment if some distance from family home, childcare for healthy children) with one parent often unable to maintain employment at all, meaning that the financial cost of sacrificing a week of pay will be too great. Instead, an employee is likely to use annual leave and see no benefit from the entitlement.

Pros for employers: Unclear if there are any advantages unless it suits the work planning schedules for some businesses. However, whatever length of leave is available, a benefit for the employer is that those with caring responsibilities are identified within the organisation and this could additionally enable managers to provide pastoral support where needed.

Cons for employers: With less flexibility for the employee, it is possible that employers will find that fewer employees take up the right to Carer's Leave. It is possible that a minority of employees may instead use sick leave if caring responsibilities are overwhelming at a particular point, and this would be less predictable and convenient for the employer than planned Carer's Leave.

A week of unpaid leave, available to take as individual days?

Pros for employees: Greater flexibility to take leave in accordance with the needs of the person that they care for, and avoids the employee incurring a week without pay where this may be too great a sacrifice for their household. They may feel less guilty for their absence if individual days are more convenient for colleagues to accommodate.

Cons for employees: None

Pros for employers: Avoids an employee being absent for longer than the care need requires, which could be wasteful. We understand that employers with existing carer's leave policy tend to make this an offer of individual days or half days. Whatever length of leave is available, a further benefit for the employer is that those with caring responsibilities are identified within their organisation which may be valuable for ensuring a compassionate approach to their line management.

Cons for employers: Would depend on the particular business/ organisation and their work planning requirements

Requesting the leave

Question 18: Do you agree that an individual should be required to give their employer notice ahead of taking Carer's Leave?

- Strongly agree **Agree** Neither agree nor disagree Disagree Strongly disagree Don't know

Please provide reasons for your answers: This would align Carer's Leave with other forms of planned leave, and provide a distinction from the provisions in Time Off For Dependents. Employers would be free to go further and not request notice if they wish to provide maximum flexibility.

Question 19. If you strongly agree or agree, what do you think a reasonable notice period would be for a block of one week of Carer's Leave? Please select one:

- 2 weeks
 3 weeks

Other, please specify: One week

Please provide reasons for your answers: Our preference would be for Carer's Leave to be available in half days and individual days, rather than blocks of a week. However, reasonable notice for requesting a block of a week might be one week. An example of when an employee may suddenly seek a period of Carer's Leave at short notice would be if a child or young person was diagnosed with cancer and required immediate treatment. This can mean a child being kept in hospital from the point of diagnosis for a course of six weeks treatment, with a relative beside them throughout. In such situations a parent would have good reason to seek Carer's Leave to share caring responsibilities for the sick child, and the provisions in Time Off For Dependents would be insufficient for the need.

Question 20. If you strongly agree or agree, what do you think a reasonable notice period would be for single day of Carer's Leave? Please select one:

Less than 1 week, please specify: We would suggest a minimum notice period of two days to take one individual day of leave.

1 week

More than 1 week, please specify: [Click here to enter text.](#)

Other, please specify: [Click here to enter text.](#)

Please provide reasons for your answers: We believe that provisions should offer maximum flexibility for the employee to respond to caring needs which arise at short notice but are outside the scope of Time Off For Dependents. We believe that most employees would provide notice as far in advance as possible but for a small minority having a shorter notice period would be reasonable and workable.

Question 21. Please comment on how employers would manage the process for requesting and recording the leave, and any associated issues, if it was:

- A week of unpaid leave, available to take as a single block? A request for leave would be made to the line manager in the first instance. An HR department would manage recording the leave and any evidence requested or supplied.
- A week of unpaid leave, available to take as individual days? A request for leave would be made to the line manager in the first instance. An HR department would manage recording the leave and any evidence requested or supplied

The impact on employers

Question 22. What benefits for employers would arise from introducing a right to unpaid Carer's Leave? Employers should anticipate greater loyalty from employees who might benefit from this leave, whether they are currently caring for someone or anticipate doing so in future, which a large proportion of employees might expect at some point in their working lives. It is worth noting that in some circumstances the care need may exist for many years with regard to a child with a life-threatening or terminal condition. Academic research has shown that , there are a growing number of young people are surviving with a life-threatening or life-limiting condition to the age of nineteen, as a result of medical advances and technology (*Make Every Child Count*, Fraser, Gibson-Smith, Jarvis, Norman, Parslow, University of York, 2020). This means a parent may experience many years of providing care while maintaining their employment, and an employer can expect the employee to place great value on their employer responding to this with compassion. Recruitment costs and sickness leave may decline, and retention rates are likely to rise. Employees may also report higher levels of job satisfaction and personal well-being, and may value having their caring identity recognised more formally. Employees tell Rainbow Trust that the attitude of their employer while they have cared for a child or young person with a life-threatening or terminal illness can make a significant impact on their own wellbeing, their loyalty to their employer, and their productivity. For instance, a parent whose daughter received cancer treatment for ten months before her death, described the impact of the situation as 'catastrophic' for the whole family but continuing to work flexibly around her daughter's treatment provided her with purpose and a sense of normality at a very difficult and distressing time. She remained with the employer for many years subsequently. Furthermore, we would hope that this policy would act as a driver for all employers to understand the impact of caring responsibilities on employees, and that this policy would be just one element in a wider package of ways in which employers could become better aware of employed carers' needs.

Question 23. What are the most significant costs for employers which would arise from a right to unpaid Carer's Leave? Please rank 1 – 4; with 1 as the most significant cost.

		4	3	2	1
The costs of administering the process (for example employees submitting requests to line managers/HR, asking for additional information, HR recording details of leave taken)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Re-organisation process/costs (reallocating work, costs of an absent employee etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Familiarisation costs (costs associated with understanding any new legislation)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The costs of employers voluntarily opting to pay for the leave	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Please provide reasons for your answers and indicate if there are other significant costs: Rainbow Trust currently allows a period of unpaid carers leave, therefore the implementation of this would be at no additional cost for the organisation. The costs of re-allocation of work would increase as the period increases. As a voluntary organisation we would not be in a position to offer paid carers leave.