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## Policy and Advocacy

# ECPC Calls on European Parliament to deliver on the Work-Life Balance Directive

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12 September 2018

The European Cancer Patient Coalition (ECPC) today calls on Members of the European Parliament to make sure that inter-constitutional negotiations starting today on the Directive on Work-Life Balance for Parents and Carers reflect the main points included in the report adopted by the Employment Committee. This proposal, released on 23 August, guarantees important protections for informal carers – those who offer unpaid care to an ill or disabled person outside of the professional framework – by providing leave and flexible work arrangements so they can balance both their careers and caring for loved ones.

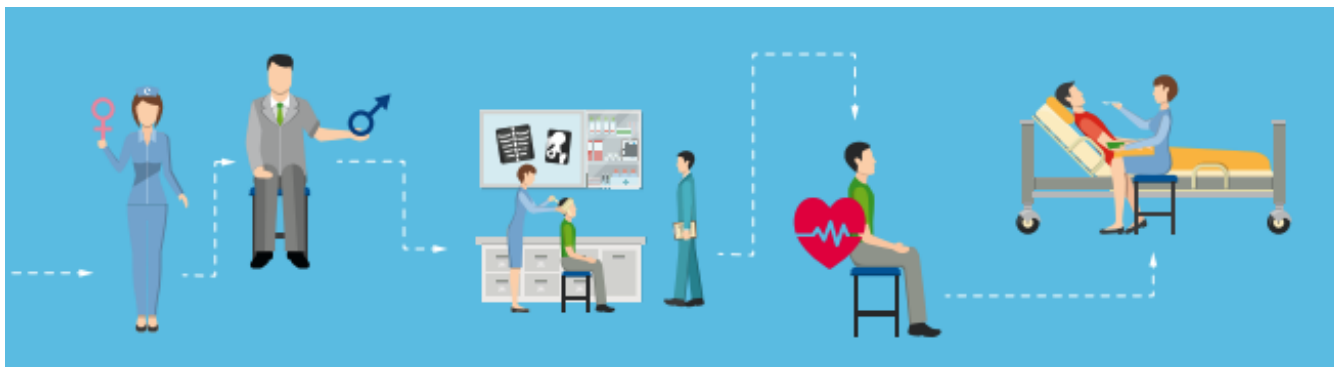
***"We are calling on the European Parliament to safe-guard provisions which will bring better recognition and protection to caregivers, especially those caring for someone living with cancer, as inter-institutional negotiations begin"*** said Francesco de Lorenzo, ECPC President. ***"The report adopted by the committee includes key ECPC recommendations, as it offers a clear definition of 'carer,' a flexible work environment, and the right to a minimum of five days of paid leave. With the increasing burden of cancer, we need urgent policy action to protect carers who now provide 80 percent of care across Europe."***



***ECPC Amendments Adopted by European Parliament Employment Committee***

<p><b>ECPC Proposed Amendment</b></p> <p><i>"carer" means a person who provides care to someone with a serious illness, disability, or dependency or care need, outside a professional or formal framework</i></p>	<p><b>Adopted EMPL Amendment</b></p> <p><i>"carer" means a worker providing personal care or support on a not-for-profit basis due to a serious medical reason, including a disability, a chronic illness or a mental health condition, as well as hospitalisation, surgical intervention without hospitalisation, or an age-related impairment, to:</i></p> <p><i>(i) a relative;</i></p> <p><i>Or</i></p> <p><i>(ii) a person from the worker's immediate circle who is not a relative, following the written request of that person.</i></p>
<p><b>ECPC Proposed Amendment</b></p> <p><i>"carers leave" means leave from work for a carer on the grounds of the need to provide care to someone with a serious illness, disability, or dependency or care need, outside a professional or formal framework.</i></p>	<p><b>Adopted EMPL Amendment</b></p> <p><i>(ca) "carers' leave" means paid leave from work for carers in order to provide personal care or support to a relative or a person from the worker's immediate circle following his or her written request, due to a serious medical reason, including a disability, a chronic illness or a mental health condition, as well as hospitalisation, surgical intervention without hospitalisation, or an age-related impairment;</i></p>
<p><b>ECPC Proposed Amendment</b></p> <p>Member States shall take the necessary measures to ensure that <b>all workers regardless of gender and including the self-employed</b> have the right to carers' leave of at least five working days per year, per worker.</p>	<p><b>Adopted EMPL Amendment</b></p> <p>Member States shall take the necessary measures to ensure that workers have the right to carers' leave of at least five working days per year, per worker. Such right may be subject to appropriate <b>medical</b> substantiation of <b>the care and support needs</b> of the worker's relative <b>or the person for whom the worker provides care pursuant to point (ca) of Article 3. The information concerning the medical condition shall be confidential and shall be shared only with a restricted number of involved services to safeguard the right to data protection of both the worker and the person in need of care or support.</b></p> <p><b>Member States' arrangements that guarantee workers the right to personal care or support for relatives or persons from the worker's immediate circle may be recognised as carers' leave in accordance with paragraph 1 if the national system offers an equivalent or higher level of protection that that laid down in this Directive.</b></p> <p><b>Member States shall assess the need to adapt or extend the definition of "carer" for the purpose of applying for the relevant leave, with the aim of taking into account situations of particular difficulty.</b></p>

## Who are Cancer Patients' Carers?



Carers currently face many challenges including the fact that, given the familial nature of most cancer care, many do not identify as carers – only 2 out of 5 identify with the term. Further, the weight of care often falls on women. Of the 100 million European carers about two thirds are women; this can often lead to gender inequality in the workplace, as caring can prevent women from taking certain working opportunities. Caregiving is also associated with a significant reduction in employment and hours of work. There is correspondingly an increased risk of poverty for people entering caregiving. Finally, the psychological burden on carers can be immense, leading to grief and stress due to the illness of their loved one.

Carers provide an enormous cost saving to health systems, but without appropriate compensation and support, the risk is this structure of care will collapse. Identifying cancer carers, valuing their contribution and creating policy to support this function in society is the key to providing sustainability of care for patients in the future. Adopting the "Work-Life Balance for Parents and Carers" directive is an important step in this direction to ensure a harmonised European framework.

## ECPC Key recommendations

ECPC is pleased with final report of the Employment Committee as it includes ECPC's three key recommendations to develop a harmonised European framework for cancer carers:

- Adopting a legal definition of a carer following the Eurocarers established definition. The term underlines the difference between 'in-patient care' provided by healthcare professionals and the care provided outside of those formal settings.
- Adopting the minimum 5 days paid carer leave, and build upon this where possible to accommodate the impact of disease such as cancer, where the burden of diagnosis may require a greater support system from family and friends
- Providing flexible work arrangements for carers, addressing the needs of those caring for a person with a chronic condition, such as cancer, to ensure that caregiving does not prohibit active employment, particularly for women.

As part of its advocacy for cancer carers, ECPC in conjunction with Eurocarers recently published a White Paper on Cancer Carers (<http://www.ecpc.org/WhitePaperOnCancerCarers.pdf>), which reflects the great challenges faced by informal cancer carers across Europe. It also outlines policy recommendations that can bring better recognition and protection of the caregivers, especially those caring for someone living with cancer. ECPC launched this White Paper in the European Parliament in November last year to great success, and as the basis for the positioning on the Work-Life Balance for Parents and Carers Directive proposal.



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