



# WHITE PAPER ON CANCER CARERS

Finding the right societal response  
to give people with cancer and their carers  
a proper quality of life



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## Executive Summary

This White Paper is a joint collaboration between the European Cancer Patients Coalition (ECPC) and Eurocarers, aimed at presenting European policy-makers at the European Union (EU) and national level with policy recommendations for a robust policy framework supporting cancer carers. Carers are people who provide unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework<sup>1</sup>. These people provide 80% of care in Europe<sup>2</sup> but the increasing burden of chronic diseases such as cancer mean that urgent policy action is needed to ensure the sustainability of caregiving.

The magnitude of this issue remains strikingly undefined and until the impact of caregiving in Europe can be measured, it will remain challenging to manage. Identifying cancer carers, valuing their contribution and creating policy to support this function in society is the key to providing sustainability of care for the future.

The challenges faced by cancer carers are a microcosm of those faced by carers across disease areas. In many cases the specific needs of cancer carers, where the psychological burden may be particularly high, are an acute reminder of the general need to support carers. This paper highlights the need for specific attention towards the needs of cancer carers and the importance of an improved framework for carers generally.

## Contributors

- Alberto Domingo, European Cancer Patient Coalition
- Carla Barbosa, Associação Portuguesa de Doentes da Próstata
- Christoffer Johansen, Danish Cancer Society Research Centre
- Claire Champeix, Eurocarers
- Francesco de Lorenzo, European Cancer Patient Coalition
- Francesco Florindi, European Cancer Patient Coalition
- Heinz Becker, Member of European Parliament
- Kathi Apostolidis, European Cancer Patient Coalition
- Jelena Burianová, Mamma help
- Lydia Makaroff, European Cancer Patient Coalition
- Marina Wittner, Assistant to Heinz Becker MEP
- Natacha Bolanos, European Cancer Patient Coalition
- Roberto de Miro, Italian Federation of Volunteer-based Cancer Organisations
- Stecy Yghemonos, Eurocarers
- Veronika Duci, University of Tirana



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### Facilitated and edited by: Kit Greenop, RPP Healthcare

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## Policy Recommendations Overview – What Can You Do?

### European Policy-makers

**Recommendation 1:** Formally recognise carers through the European Pillar of Social Rights, as one of the cornerstones of health and long-term care systems across Europe.

**Recommendation 2:** Recognise the importance of caregiving by using EU mechanisms (EU Funds, Parliamentary studies, Programmes, projects, Monitoring Reports etc.) to raise awareness about caring issues and identify carers across the EU.

**Recommendation 3:** Fully support the European Commission's legislative proposal on Work-Life Balance which includes, among other supporting measures, a harmonised minimum 5 days of paid leave per year for carers across the EU.

**Recommendation 4:** Promote the development of tools and indicators to measure the implementation of the European Pillar of Social Rights in Member States with regards to Work/Life balance for carers, as well as the actual access of carers to other social rights listed in the Pillar.

**Recommendation 5:** Recognise the importance of caregiving on long-term sustainability of care by monitoring its impact on the Europe 2020 goals through the European Semester and by taking into account the role of caregiving in the implementation of the European Employment Guidelines.

**Recommendation 6:** Ensure that European funds are made available to initiatives supporting carers at national and local levels including carers of people with severe conditions such as cancer, notably through adequate training, exchange of information, research and networking.

### National Policy-makers

**Recommendation 1:** Adopt a formal status of a carer which encompasses caring for patients with severe conditions such as cancer, in order to recognise and value this group of people who are fundamental to the sustainability of health and long-term care.

**Recommendation 2:** Initiate carer identification programmes, including the identification of cancer carers, to ensure carers are supported adequately and have access to relevant national programmes.

**Recommendation 3:** Adopt the minimum of 5 days of paid carer leave, and build upon this where possible to accommodate the impact of diseases such as cancer where the burden of diagnosis may require a greater support system from family and friends.

**Recommendation 4:** Provide 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.

**Recommendation 5:** Ensure appropriate pension rights for carers where time in employment has been lost due to long-term care.

**Recommendation 6:** Entitle carers to appropriate health insurance to help prevent and alleviate the mental, psychological and physical burden they experience.

**Recommendation 7:** Introduce a robust carer support programme including training, psychological support and financial support, as well as access to health and care public services, and the inclusion in a patient's care team.

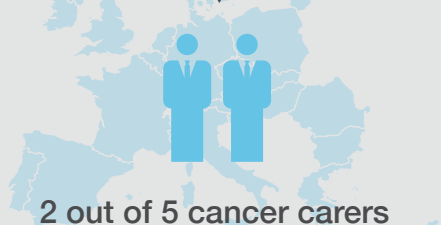
## Introduction

Europe faces a future of increasing challenges: an ageing population, increasing cancer prevalence and widespread inequalities. The increasing life expectancy in Europe is a huge achievement but is accompanied by challenges for healthcare and social security systems. Identifying where policies can increase the sustainability of care is essential to mitigating these challenges for European citizens.

Traditionally, healthcare and support for people with chronic illnesses, including cancer, has been provided at care institutions by trained health professionals. However, as resources for inpatient (in-hospital) services have become limited, there has been a shift towards services being provided on an outpatient basis. In the case of cancer care, this shift has necessitated the use of cancer carers, typically family members or close friends of the patient, to assume many of the home healthcare services. To develop effective policy for this shift in care, policy-makers must look beyond traditional healthcare pathways and employment policies and acknowledge that carers continue to provide a substantial portion of care across Europe<sup>3</sup>. While people with cancer are identified through diagnosis, cancer carers often remain largely anonymous despite the fundamental role they play in the healthcare pathway. Cancer carers form an integral part in the management of this devastating disease.

Examples throughout this paper show how aggressive and long-lasting forms of cancer impart a particular burden on carers requiring a robust framework to support their role. This is highlighted in this paper through the example of metastatic cancers<sup>4</sup> where both the person with metastatic cancer and the carer require holistic support to manage an enduring psychological and physical burden. Without carers, people with cancer would miss out on an invaluable resource and health systems would be unable to sustain the burden of care<sup>5</sup>. To ensure Europe supports these fundamental actors, policy actions at European and national level are needed to identify and empower cancer carers to provide flexibility and choice where historically duty and need have often devalued and constrained carers.

## The Challenges for Carers



2 out of 5 cancer carers identify with the term 'carer'

### SELF IDENTIFICATION AS A CARER

Given the familial nature of much cancer care, and the often-presumed social responsibility of care, many carers do not identify as carers. In fact, in some European countries only around 2 out of 5 cancer carers identify with the term 'carer'<sup>6</sup>. The lack of a defined group presents a monumental challenge in developing appropriate policies for carers.



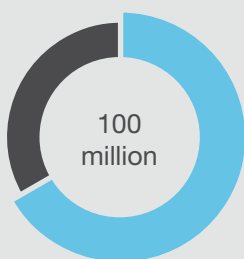
Caregiving



cost saving

### COMPENSATION AND SUPPORT

Caregiving represents an enormous cost saving to health systems<sup>7</sup> but the growing burden of diseases means that, without appropriate compensation and support for carers, this structure of care risks collapsing.



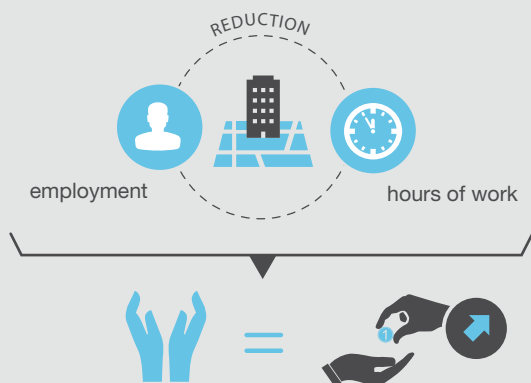
100 million



45-75 years old

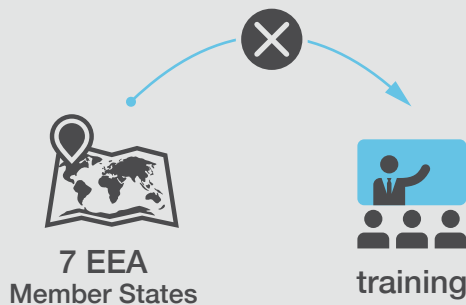
### GENDER ISSUES

Of 100 million European carers, about two thirds of them are women between ages 45 and 75<sup>8,9</sup>. This gender inequality leads to a disenfranchisement of women in the workplace as the burden of care prevents them from taking certain working opportunities and actively participating in other family activities or broader society.



### FINANCIAL TOXICITY

Caregiving is associated with a significant reduction in employment and hours of work. There is correspondingly an increased risk of poverty for people entering caregiving<sup>10</sup>.



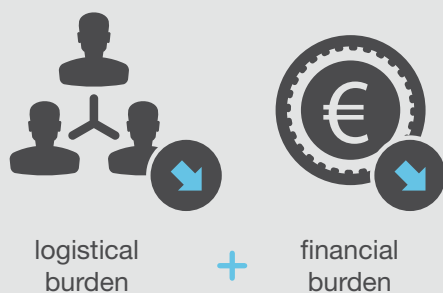
#### LACK OF INFORMATION

7 EEA Member States<sup>2</sup> do not offer training for carers<sup>11</sup> meaning that carers either risk providing care which may result in adverse consequences for the patient or themselves, or spend time at expensive hospital visits for routine procedures.



#### IMPACT ON PHYSICAL HEALTH AND EMOTIONAL HEALTH

The psychological burden on carers is immense; carers must deal with financial pressures as well as the burden of new diagnoses of those they are caring for. This can lead to anticipatory grief and stress, amongst other psychological issues. In cancer care, metastasis causes immeasurable grief in patients, due to the unexpected return or spread of the disease<sup>12</sup>. To manage such a complication, patients and their carers require robust psychological and physical support.



There are also significant financial and logistical burdens, as the carer may need to reduce the amount of time they spend in their own work and family responsibilities as they are required to take on roles formerly held by the dependent and/or provide time consuming care and support for the dependent. As noted, these often include monetary, and emotional support factors. Despite these complex and multidimensional burdens, many social care systems do not accommodate provisions for these carers in their health insurance or in general access to health services.

## Cancer Carers

### Who are Cancer Patients' Carers?



#### DEFINITION – PROVIDED BY EUROCARERS

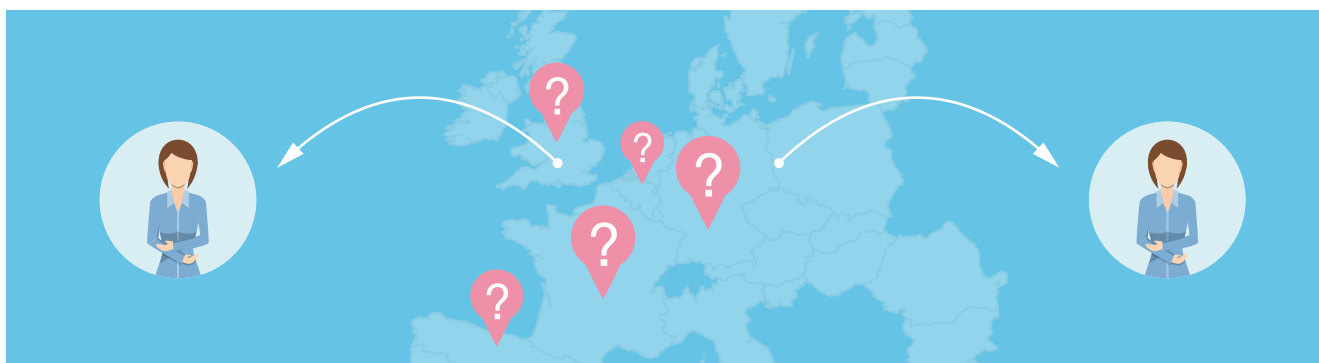


**A carer is a person who provides unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework.**

In much of the scientific literature regarding carers, the term “informal carer” is used. The term underlines the difference between ‘in-patient care’ provided by healthcare professionals and the care provided outside of those formal settings. Eurocarers specifies that the term “informal” indicates that there is no regulation, working hours, holidays, labour conditions, pay or other benefits derived from the care. “Informal carers” are “informal” because there is no legal framework to support them in their work.

However, “informal” does not suggest that these people are less effective carers. The authors of this paper believe that such differentiation might mislead the reader regarding the key role that carers have in the overall management of the patient’s disease and outcomes. In fact, carers do not receive the same degree of training as and thus must learn independently how to provide care to their families and friends. While this does not diminish the importance of their contributions, it does place additional burden on them to acquire requisite skills to adequately provide support to their loved ones with cancer. While we recognise that, from a legal and scientific standpoint, the term “informal carers” represents a well-established standard, we will use “carers”. Therefore, carers can be understood as stated in the definition above.

### Who are Europe’s Carers?



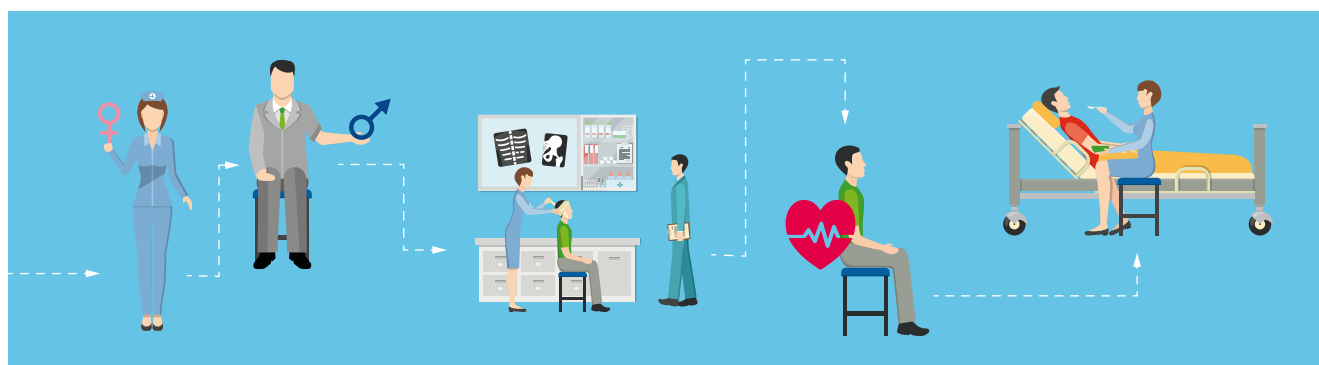
Carers are often partners, parents, children, children-in-law, grandchildren, siblings, friends or neighbours. These carers are currently providing around 80% of care across the EU<sup>13</sup>. A typical carer is a woman between 45 and 75 years of age<sup>14</sup> and, despite the growing number of carers in the EU, caring is mostly provided by spouses, middle aged daughters or daughters in law as women represent about two thirds of all carers<sup>15</sup>. There are currently more than 100 million carers in Europe, a largely underestimated figure given the (self-)recognition problem of carers.<sup>16</sup>

In comparison with other diseases, cancer patients have organised themselves more frequently into a great number of well organised associations, charities, trusts and federations, to provide practical support to patients and their families.

While cancer carers' efforts vary depending on the situation of the cancer patient, in general, carers provide the following services:

- Completing home healthcare tasks (nursing, sometimes medical tasks)
- Ensuring treatment compliance and continuity of care
- Providing physical/personal care
- Supporting/providing mobility/transportation
- Providing emotional/psychological/social support
- Providing domestic care
- Financial management and support
- Organising and managing care and support

## Challenges Faced by Cancer Patients' Carers



### Gender issues

The spouse is often the primary carer for cancer patients<sup>17</sup>. Female spousal carers report higher level of negative experiences in caregiving, such as poorer mental health, physical health, health-related quality of life, life satisfaction and decreased marital satisfaction, compared to male spousal carers<sup>18</sup>. Furthermore, female spousal carers for cancer patients report higher levels of negative experience in caregiving<sup>19</sup>. Nonetheless, female spousal carers are also much more likely to take on this role due to societal pressures<sup>20</sup>. A better understanding of how gender influences the caregiving experience could provide policy-makers and healthcare professionals with targeted information to support and prepare spousal carers.

The negative issues of gender-determined caring are felt particularly by young women (15-25 years old) who are called to assume the role of a carer and who consequently may abandon studies or not look for active employment. Indeed, in the United Kingdom (UK), 41% of young carers were 'unsure' whether they could afford to go to university<sup>21</sup>. The aforementioned gender-specificity of the caregiving role means that more girls than boys take on this role at a young age, leading to inequalities in the access to employment opportunities.

### Impact on physical emotional health

While most carers provide excellent care in their caregiving role, this often comes at the price of becoming highly distressed or developing an affective disorder<sup>22</sup>. Cancer carers are known to have high needs and psychological morbidity<sup>23</sup>. Carers are often required to assume numerous roles and make many changes in their lives. By being practically and emotionally involved, however, carers' own lives are often affected to an overwhelming extent.

The physical, emotional, social, and financial stress that carers can face in this role may result in the neglect of their own needs, adversely affecting their own quality of life.

When surveyed, cancer patients and carers<sup>24</sup> have reported anxiety, depression and somatization; unmet supportive care needs; and cancer-specific distress. Carers have also reported post-traumatic growth, which refers to the positive aspects of providing care, including increased sense of purpose and higher self-esteem. Nearly half of carers reached “caseness” (that is, they would meet the criteria for a formally diagnosable condition) in anxiety, depression or somatization. Carers had higher distress ratings and intrusive thinking compared to people with cancer. Social support networks are a crucial moderating factor to this anxiety and as such free time to keep such networks is an essential solution to mitigating the impact on physical and emotional health.

## Socio-economic disadvantages

There is clear data highlighting the socio-economic difficulties faced by cancer carers<sup>25</sup>. In 2009, cancer cost the EU €126 billion. Of this, €75 billion was shouldered by patients and their families, including carers. Meanwhile, productivity losses cost European families €42.6 billion, and loss of working days €9.43 billion. Caregiving costs were valued at €23.2 billion<sup>26</sup>. In this study, caregiving was defined as the opportunity cost of unpaid care – i.e. the working or leisure time that carers forego to provide unpaid care valued in monetary terms. European families therefore pay three times for the consequences of cancer: first, the patient sustains the loss of income and of years of life due to the illness; second, the carer forfeits economic advantages through loss of income and loss of working days; finally, all family members pay taxes that only partially cover the costs of cancer care.

Carers may also face additional socio-economic difficulties including the lack of health insurance where caregiving is not considered a state of ‘employment’. Such health insurance is essential in providing carers with the psychological and physical health support that is often needed when caring for family and friends<sup>27</sup>. Furthermore, carers may often be negatively impacted by their choice to provide care when it comes to receiving pensions<sup>28</sup>. This type of socio-economic disadvantage makes the indispensable role of carers less sustainable and risks making this group even more vulnerable to economic difficulties. In order to ensure the sustainability of caregiving, carers must be able to receive a pension which recognises that the years caregiving were not ‘unemployed’.

## Lack of information and training

### Coping with patients’ self-perception as a “burden to others”

Among Europeans with advanced cancer who had less than one year to live, “being a burden” ranked third among self-reported symptoms, right after pain and breathlessness<sup>29</sup>. Therefore, patients living their last year of life with cancer are not only concerned about medical problems but also about being a burden to their carers. Cancer care should include a routine assessment and management of social concerns, particularly for older people with poor prognosis.

### Managing malnutrition

Acknowledging also that malnutrition is a major issue for cancer patients, awareness should be raised amongst carers about the issues related to weight loss and cachexia (marked weight loss in patients with cancer that cannot be reversed by normal nutritional support)<sup>30</sup> which reduces tolerance of cancer treatment and decreases the likelihood of response. Practical advice should be made available to carers on how to address nutrition issues.

### Feeling unprepared/uninformed as a carer

While many people are willing to act as carers, a large number of them may be unprepared for this task. Studies show that in countries such as the UK, up to 22% of carers deal with specific healthcare tasks such as administering medicine and pain relief as well as giving injections and over 50% of these have not received information, or training<sup>31</sup>. Simple training such as on how to administer medicine and give injections avoids unnecessary trips to the hospital and will make the carer feel more prepared to deal with these challenges.

## Building a Policy Framework for Carers

Achieving an appropriate framework for caregiving requires policy-makers to address four core challenges: Identification, Valuation, Compensation and Support. These four principles should be engrained in national strategic health and employment plans as well as in all social protection and social inclusion policies.

### Identification



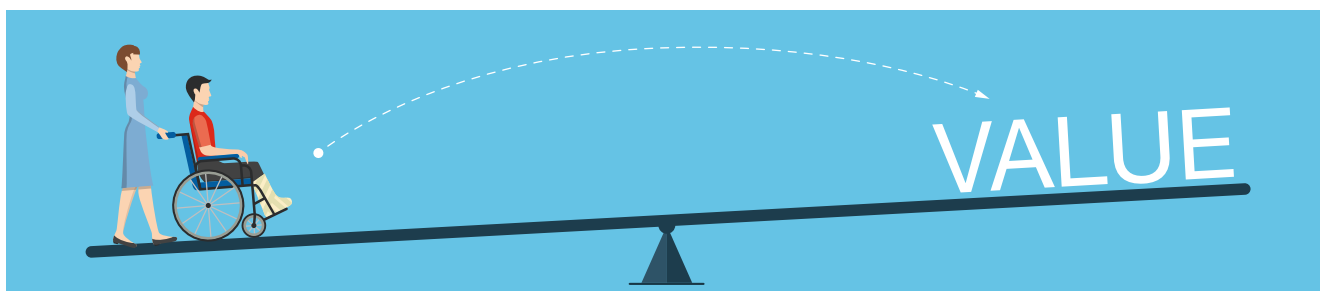
Having an effective, inclusive definition of a carer is fundamental to managing caregiving in Europe. This is because any support or compensation made available to carers in turn ensures the sustainability of caregiving. Therefore, the burden to identify and receive available support should not be placed on the carer but rather an appropriate definition should assist national governments to identify and support carers through all available means foreseen by the Member State. If, as shown in studies in the UK, only around 40% of cancer carers identify with the term ‘carer’<sup>32</sup>, this means that only a portion of all carers will proactively seek support and guidance to fulfil their role, based on their self-identification as carers. Therefore, relying on self-identification to ensure that carers are supported will not be sufficient in over half of the population.

Identification of carers must therefore follow three key steps:

1. Adopt a legal definition definition of a carer, following the Eurocarers established definition: “a person who provides unpaid care to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal framework.”<sup>33</sup>
2. Initiate active information campaigns and networks to ensure that carers are aware of their status, rights and support mechanisms.
3. Support the development of carer organisations, engage with carers and support the projection of their voice in policies.

While such an approach may be perceived to increase costs, it is well documented that support for carers is not a cost but rather an investment<sup>34</sup>. In order to effectively support carers, this investment in identification must be followed by an appropriate valuation of the support carers provide to society.

### Valuing Care



The sustainability of caregiving depends upon recognition of its value. When individuals choose to take on the responsibility of caregiving, governments need to recognise the value of this work to the health system and broader society. In 2011, in the UK, the unpaid care provided by carers was estimated at £119 billion per year, which was considerably more than the total spending on the National Health Service<sup>35</sup>, calculated at £98.8 billion in the year 2009-2010<sup>36</sup>. While caregiving saves the healthcare system an extraordinary amount of money, it must also be recognised that supporting carers who want to continue to work will also provide an important economic stimulus. In the UK, the loss of work due to care was estimated at £1.3 billion per year, compared with a potential gain of £5.3 billion per year if carers are supported to work.<sup>37</sup> This phenomenon is present across Europe as an Italian Survey<sup>38</sup> valued the activity of carers at €12.3 billion per year and the financial toxicity for families of ill people (including carers) above €34 billion. Therefore finding a balance between promoting caregiving, and providing opportunities to remain in the labour market is crucial.

In many diseases like cancer, the value of carers is priceless, as the value of having a family member or close friend providing care cannot be replaced. For this reason, it is fundamental that those providing care are valued and supported.

### Compensation and Support



Support must be available for all carers. Policies must simultaneously provide opportunities for people to be fairly compensated for their caregiving work and benefit from flexibilities to work and care, and ensure access for all to quality long-term care services in the community for those who cannot or do not choose to care.

Providing monetary compensation for carers is essential in valuing their contribution to society, reducing financial toxicity of carers and improving the sustainability of long-term care. However, monetary compensation cannot be the only financial support provided to carers: cash benefits may risk discouraging carers from returning to work in order not to lose the cash benefit therefore trapping carers, most notably women, in a socially precarious and at times unwanted caregiving role.<sup>39</sup> Losing this demographic from the workforce is not only socially discriminatory but also reduces the government's potential return from the labour market.<sup>40</sup> Incentivising high levels of employment, especially in demographics where traditionally caregiving has been an obligation, is essential to removing the gender bias from caregiving and as such, opportunities must exist for women to take up gainful employment while offering occasional caregiving if they should choose to do so. This requires flexibility from employers allowing occasional leave for family members to support patients with new severe diagnoses such as cancer. It also requires investment from governments in health and care services including qualified nurses to take up care where caregiving is not available or inadequate (e.g. in complex care situations). Some countries are elaborating legislative proposals in this direction. This is the case of Italy where a legislative proposal was put forward in April 2016<sup>41</sup> that would recognise and protect the work done by carers towards their family members as well as the economic and social contribution of the community.

Finally, support must be available to deal with the very real burden of caregiving on the health of the carer. Personalized multicomponent interventions for caregivers are needed, given their pivotal role for cancer patients. Carers are very likely to experience feelings of isolation and psychological distress including anxiety, depression and loss of self-esteem.<sup>42</sup> For example, many carers dealing with people with brain tumours are physically, cognitively and emotionally impaired<sup>43</sup>. Consequently, appropriate respite care and 'care for carers' must be a fundamental part of health plans. Such a prevention oriented approach will help avoid further human costs.

## EU Approach – Developing a Harmonised European Framework for Cancer Carers

### European Framework



The European Union (EU) holds a crucial role in improving social policy across the Member States and therefore in enhancing the support for cancer carers across Europe through changes to common social and employment policies. The European Union's governing treaty, the Treaty of the Functioning of the European Union (TFEU) regards promoting employment and guaranteeing adequate social protection as a matter of common concern across Member States and hence provides the EU with coordination mechanisms to this effect.<sup>44</sup> The EU further commits through this treaty to equality between men and women with regards to labour market opportunities and treatment at work.<sup>45</sup>

The EU has established several flagship initiatives to promote enhanced employment and gender equality across Europe. These include the Europe 2020 strategy<sup>46</sup> on employment and the Strategic engagement for gender equality 2016-19<sup>47</sup>. Targets include raising the employment rate of the population aged 20-64 to at least 75% and the promotion of the economic and social rights of girls and women. If these policies are to be successful, then the societal valuation of caregiving and the policy solutions to empower carers must be addressed.

This topic has been raised at European level previously through the 2013 European Parliament Own Initiative Report on the 'Impact of the crisis on access to care for vulnerable groups'<sup>48</sup> and more recently in the 2016 'European Parliament report on women domestic workers and carers in the EU'<sup>49</sup> which have set the basis for increased European action to standardize the rights of carers across the EU.

### European Tools to Identify, Support and Empower Carers



In 2016, the European Commission introduced the European Pillar of Social Rights<sup>50</sup> to deliver new and more effective rights for citizens in the areas of:

- Equal opportunities and access to labour market;
- Fair working conditions;
- Social protection and inclusion.

The European Commission recognised the need to both adapt the European legal framework to trends in work patterns and to provide specific measures to the expectation of encouraging and supporting women's participation in the labour market. Therefore, as part of the package of initiatives launched together with the European Pillar of Social Rights the European Commission has developed a legislative proposal on Work-Life Balance of Parents and Carers. The proposal for a Directive on the Work-Life Balance for Parents and Carers<sup>51</sup> includes the introduction of 5 days of paid leave for workers caring for a seriously ill or dependent relative. This proposal is an excellent breakthrough in terms of establishing a minimum standard across Europe, and will allow Member States the flexibility to build on this proposal to enhance national objectives of increased employment and gender equality.

How Member States can best interpret this pillar with relation to cancer carers is further explored in the next Chapter.

The proposed Directive should be strongly supported by Member States as it would be a breakthrough in developing and benchmarking adequate policies to support carers. This proposal for a legislative measure is backed by a series of non-legislative measures that are likely to support the Member States in achieving work life balance for parents and carers.

### Recommendations to the EU Institutions on the European Pillar of Social Rights



Generally, the proposed Directive on a Work-Life Balance for Parents and Carers must be resolutely supported and adopted in order to provide a necessary European framework. Where amendments may be pursued in the European Parliament or in the Council of the European Union, they should look to enhance in every way possible the recognition and support of carers. As such the core recommendations for the European Institutions are to:

- Recognise the European Pillar of Social Right as the reference framework for policy making at the EU level in the coming years.
- Adopt the proposed Directive on a Work-Life Balance for Parents and Carers and in order to enhance its value to carers, adopt the Eurocarers definition of a carer;
- Develop the legislative and non-legislative tools needed for the implementation of the European Pillar of Social Rights, including monitoring tools to analyse the implementation of these rights, by Member States, as well as exchange of experience and good practices;
- Once the Directive on Work-Life Balance for Parents and Carers is adopted, its implementation should be carefully monitored, and the business case of supporting working carers through special leaves and flexible arrangements should be promoted towards enterprises. The European Commission should facilitate the exchange of good practice of how employers can manage more flexible work arrangements (including flexible working hours and flexibility on the place of work) and why the support to carers may be positively included in national employment policies. As such, several of the national examples noted in this paper could be ideal best-practices;

## Implementing the Social Pillar – the Role of the Member States

Given the legal nature of the Social Pillar, all rights and principles are not directly enforceable and require implementation through distinct legislative and non-legislative instruments at the national level. As such, this paper looks to offer a proactive interpretation of the provisions proposed in the Social Pillar with three key objectives in mind:

- Supporting the sustainability of caregiving by providing carers with flexibility at home and at work;
- Enhancing patient care and quality of life by ensuring carers are supported and trained;
- Facilitating a productive and healthy workforce through flexibility at home and at work.

Consequently, the next section of this paper looks to identify how national governments could interpret the provisions in the Social Pillar to develop the most robust policy for carers.

## Member State Approach - Developing Sustainable Policies for Cancer Carers

While EU efforts to improve social policy are crucial, it is the Member States that will have the final say on adopting and interpreting the Directive on Work-Life Balance of Parents and Carers and any other initiatives relating to employment and health into national law. Furthermore, there are a myriad of topics which fall beyond the scope of the Directive on Work-Life Balance of Parents and Carers, such as insurance issues, pension claims and the integration of carers into a patient's official 'care team'.

Consequently, this section proposes concrete recommendations on how Member States can provide a sustainable framework to support carers and maintain a fair employment and social policy. Improvements to policy in these areas would provide direct support to carers as well as to people with cancer by equipping their carers to provide adequate care.

### National Tools to Identify, Support and Empower Carers



#### Formal recognition of carers

As noted in the section on 'Identification', recognising carers provides the Member State with an opportunity to manage the situation of caregiving, rather than be subject to the negative impacts of unsupported caregiving. These impacts include reduced employment levels in the labour market, disenfranchisement of women, financial toxicity in households and increasing levels of mental health issues. Therefore, the first step in providing a framework for caring is adopting a definition to mark a formal status of carers using as a starting point the Eurocarers definition of a carer. Twelve EU Member States have a formal recognition of carers<sup>52</sup> and the others must follow. This policy must be seen as a means to support the labour force as well as enhancing social policy.

Such a status clearly requires an eligibility test but should not be designed to discourage self-identification as a carer. Governments should consult national patient and carers organisations when developing guidelines around eligibility for carer support. Eligibility for this status may be as simple as having a family member, dependent, or friend who requires support outside of the context of structured care including: psychological support, assistance with everyday chores, providing transport and many other tasks. For example, metastatic cancer often generates a great psychological burden on a patient, requiring support beyond that of structured care and specifically needing the flexibility for family members to support them at home<sup>53</sup>. Furthermore, family caregiving may be particularly important when the treatment duration is extended due to factors such as metastasis. In these cases, hospital visits may be required on a regular basis over a long period of time, which requires the support of family members. Importantly, several national plans make a disability score a prerequisite for paid caregiving leave. Given the enormous burden that cancer places on a carer, such severe illnesses must also form part of the eligibility criteria.

The identification of eligible carers should be made by a health professional along with the patient. Integrated health, care and social services should then be made accessible to the patient and their carer.



### CASE STUDY – FRANCE:

As of January 1, 2017, the law passed in 2015 “Relative à l’adaptation de la société au vieillissement” (the adaptation of society to ageing) entered into force, granting carers new employment rights. These new rights, entitling carers to part time work arrangements or extended periods of unpaid contract suspension to care for relatives, exist due to the adoption of a formal definition of carers.<sup>54</sup> This change indicates a development in recognising the value of carers but could be further improved by extending the definition (which currently relates to elderly and disabled) also to severe illnesses such as cancer. In the Netherlands for example, the eligibility extends to serious illnesses such as cancer<sup>55</sup>. In France, this issue is being addressed in the new national Cancer Plan which will mobilise and modify the Labour and Social Security Codes, to broaden access to part-time work and time-off for employees with cancer or carers<sup>56</sup>.

## Carer identification programmes

While no one can be required to accept support for their activities as a carer, governments must ensure that all persons caring for cancer patients are aware of these support programmes. As such, information campaigns must be initiated to make health professionals aware of their responsibility to inform family members of opportunities to adopt the status of a carer. A simple, comprehensible online resource within the Department of Health also facilitates self-identification of carers and should be publicised.

Furthermore, patient groups must include these provisions in communications with their members to ensure all carers are applying for support where appropriate.

## Minimum standards of paid carer leave

The day that a patient receives a diagnosis of cancer may well be considered the most difficult day of their lives and even more so for metastatic cancer, where this day may come again and where the psychological burden may seem insurmountable. In these cases, the added quality of life provided by simple companionship and psychological support is invaluable. Providing a short period of paid leave for carers to support newly diagnosed patients is crucial alongside sporadic leave to care in emergency cases. Particularly in late stage cancer, a period of leave is essential to make family arrangements to care for people with cancer as such diagnoses drastically change the way a family needs to operate<sup>57</sup>. Therefore, while the proposal of 5 days should absolutely be supported, national governments are encouraged to look towards providing two weeks of annual paid leave or other forms of reduction of working time, to help support patients and develop family arrangements and plans for care provisions. Such flexibility would also alleviate the level of stress for carers when they return to work, consequently enhancing their productivity and value at the work place.



### CASE STUDY – NETHERLANDS:

The Netherlands has a strong policy for carers, granting paid leave up to 10 days per year, the eligibility for which extends to caring for a sick relative. Subsequently, the Netherlands has a minimum policy of 12 weeks where an employee can take up to half the number of hours they work to care for a first-degree relative.<sup>58</sup>

## Flexible work arrangements

In certain cases of cancer, the needs of patients may be longer term and require sporadic support from family members, dependents or friends<sup>59</sup>. Employed carers who spend more than 10 hours caring a week are at significant risk of leaving their jobs<sup>60</sup>. Therefore, support from employers for flexible work arrangements (including flexible working hours and flexibility on the place of work) for persons with an ‘carer status’ are essential to increasing productivity at the work place and retaining staff.<sup>61</sup>

Recognising that most of the population who are carers are in their most productive stage of life with the greatest experience and added value to employers,<sup>62</sup> employers must be encouraged to retain carers under conditions of flexible employment. Such a policy will retain crucial knowledge within companies and, for the State, it will avoid the exodus from the workplace leading to lower unemployment and greater financial toxicity.



#### **CASE STUDY – ITALY:**

Italy has passed Regulations<sup>63</sup> allowing cancer patients working in the private and public sector to switch from full-time to part time employment and to reverse to full-time employment according to their needs. This legal framework also covers carers, granting them priority over part-time applications so long as positions are available.<sup>64</sup>

### **Appropriate pension regimes**

It is important to recognise that many carers contribute over a long period of time to the health provision for patients which, due to the incomplete policy framework for carers, often means carers will not be employed for several years. Considering that this work is fundamental to the health system, it should not be punished by a lack of access to pension at the retirement age. Therefore, the time spent caring for a patient which has negatively affected the carer's ability to actively work should also open the right for a pension at retirement age.

### **Provision of healthcare and health insurance**

The European Parliament report on women domestic workers and carers in the EU called on “all Member States to include...carers in all national labour, healthcare, social care, insurance, and anti-discrimination laws”<sup>65</sup> This is because several Member States continue to exclude insurance provisions for carers. Considering the burden placed on many carers, foreseeing the need for additional health services is essential. In this respect, several countries entitled carers to sickness insurance<sup>66</sup> which is particularly important when looking at the psychological support required for caring for cancer patients.

### **Carer support services**

The final crucial provision to include within the national framework for carers is the support for carers themselves, the so called ‘care for carers’. This requires access to quality long-term care services in the community which both supports carers and provides services replacing carers. The support for carers takes several forms:

- the training and knowledge support for carers;
- the counselling and psychological support for carers;
- the integration of carers into the healthcare team.



#### **CASE STUDY – FRANCE:**

The new national plan against cancer (2014-2019), which includes an investment of €1.5 billion provides respite facilities to family carers. It commits to developing accommodation facilities for those farthest from health centres with support also for their families<sup>67</sup>.

#### **a. Training**

In the EU, at least 8 Member States do not provide training for carers<sup>68</sup>. Such training must be available to provide practical skills to carers based on the condition of their dependent as well as to value and give recognition to the skills they have already gained through their caring experience. Knowing that such information will help avoid adverse events, and reduce costs for the healthcare system, this investment must be prioritised for any person identified as a carer. Studies show that in some countries, up to 22% of carers deal with specific healthcare tasks such as administering medicine and pain relief as well as giving injections and over 50% of these have not

received information, instruction or training<sup>69</sup>. Simple training such as on how to administer medicine and give injections avoids unnecessary trips to the hospital and homecare can drastically reduce these costs.

More specifically, depending on the disease area and stage, training for conditions such as cancer must be provided specifically as well. In cancer, essential training for carers may include:

- Programmes to increase and improve carers' understanding of the needs and concerns of their loved ones and development of skills and aptitude in providing support to the patient in these areas;
- Programmes to increase and improve carers' communication skills, both with members of the patient's formal health care providers as well as with members of the patient's family and friend network who may be able to be called upon to provide relief and/or help to the carer;
- Programmes to increase and improve carers' ability to recognise and manage their own mental, physical, and social (including work) needs and concerns, and to develop skills to address these issues adequately to avoid burn-out amongst carers themselves.

While this training is crucial, safety nets such as nurse telephone services and home visits from trained medical professionals are important provisions that carers may refer to as well as having local support groups. Local support groups may congregate based on disease areas but may also be more widely associated for those providing care to their dependents.

Carers organisations, who play a crucial role in providing training and support, notably through the facilitation of local supports groups and the development of on-line tools and support, should be supported by public authorities, and should be part of the decision-making process related to health and care provision. Exchange and cooperation between patient associations and carers groups should be facilitated.

## b. Psychological support

Sustaining the psychological support for carers is essential for their wellbeing, that of their dependent and for their ability to engage in the labour market. Consequently, the health-insurance provisions discussed above must include access to stress reduction programmes, cognitive behavioural therapy or other therapies as recommended by healthcare professionals, and counselling. Taking up preventive health measures becomes more crucial as carers take on the weight of supporting patients with especially burdensome diseases such as metastatic cancer. Illnesses that endure for months or years put enormous stress on families and the longer this stress lasts, the more risk-prone carers become to mental distress<sup>70</sup>. These carers are also more prone to risky behaviour such as smoking or to neglect their own health<sup>71</sup>.

As such, health insurance for carers must integrate psychological support as an essential investment in the sustainability of caregiving.

## c. Integration in the healthcare team

The final element of support for carers is their integration in the patient's official care team which typically comprises a specialist, a General Practitioner (family doctor), a nurse and the patient. While such a designation must be included in the State's provisions around the status of a carer, much of the responsibility in this area relies on healthcare professionals. The prevailing advice for healthcare professionals is to flag the notes of carers, treat them as team members in the care for patients, include them in crucial discussions and give carers choices about tasks they are willing to take on<sup>72</sup>.

## Member State Recommendations



- **Adopt a formal status of a carer which encompasses caring for patients with severe conditions such as cancer.** Importantly, several national plans make a disability score a prerequisite for paid caregiving leave. Given the enormous burden that cancer places on a carer, such severe illnesses must also form part of the eligibility criteria.
- **Initiate carer identification programmes:** Government-sponsored and supported information campaigns must be initiated to make health professionals aware of their responsibility to inform family members of opportunities to adopt the status of a carer.
- **Adopt the minimum of 5 days of paid carer leave, and build upon this:** The European Commission's proposal of 5 days per year should absolutely be supported as a baseline
- **Provide flexible work arrangements for carers:** Support from employers for flexible work arrangements for persons with a 'carer status' are essential to increasing productivity at the work place and retaining staff<sup>73</sup>.
- **Ensure appropriate pension rights for carers:** Time spent caring for a patient which has negatively affected the carers ability to actively work should also be open to the right for a pension at retirement age.
- **Entitle carers access to appropriate health services and insurance:** Several Member States continue to exclude insurance provisions for carers. Considering the burden placed on many carers, foreseeing the need for additional health services is essential.
- **Introduce a robust carer support programme:** States must introduce support for carers themselves, including access to quality long-term care services in the community which both supports carers and provides services replacing carers. The support for carers should cover several critical services, including:
  - ➔ Training and knowledge support for carers;
  - ➔ Psychological support for carers;
  - ➔ Integration of carers into the healthcare team.

## Conclusions

The impact of caregiving on health systems is enormous, and the support that carers offer to people with cancer is irreplaceable. This makes effective policy frameworks for carers essential. This paper demonstrates the importance of caregiving in patients with cancer where the growing burden of disease makes the ability for family and friends to support patients even more important. Solutions to these challenges are outlined in recommendations on employment, social, healthcare and educational policy which will support caregiving across Europe.

At both European and national level, there are important policy recommendations to be endorsed which will allow a better functioning and sustainable care system and a fairer, more productive, economy. The care provided by friends and relatives in Europe cannot be replaced, and nor should it be, but providing carers with choice and support will ultimately result in giving people with cancer and their carers a proper quality of life.

## NUMBER OF CARERS AND EXISTING SUPPORT MEASURES ACROSS THE EU

Country	Official number		Unofficial number		Formal recognition of carers	Financial remuneration		Leave to care		Pension credits for care time	Flexible working arrangements
						Care Allowance (direct)	Attendance Allowance (indirect)	For dependent relatives	For terminally ill relatives		
AT	290.000	3,50%	837.116	9,80%	✓	✗	✓	✓	✓	✓	—
BE	420.000	4%	1.358.830	12,10%	✓	✗	✓ Regional and local level	✓	✓	✗	—
BG	N/A	N/A	N/A	N/A	✗	✗	✓	✓	✗	✗	—
HR	N/A	N/A	N/A	N/A	—	—	—	—	—	—	—
CY	N/A	N/A	N/A	N/A	✗	✗	✗	✓	✗	✗	—
CZ	281.000	2,70%	1.263.600	12%	✗	✗	✓	✓	✗	✓	✓
DE	3.256.000	4%	8.907.800	11%	✓	✓	✗	✓	✗	✓	—
DK	20.000	0,40%	524.799	9,30%	✓	✓ local level	✗	✓	✓	✓	—
EE	N/A	N/A	N/A	N/A	✗	✓ local level	✗	✓	✗	✗	—
FI	N/A	N/A	350.000	6,30%	✓	✓ local level	✗	✓ local level	✗	✓	✓ local level
FR	2.102.000	3,30%	7.115.500	10,70%	✓	✗	✓ regional level	✓	✓	✗	✓ local level
EL	273.000	2,50%	947.430	8,70%	✗	✗	✓	✓	✗	✗	—
HU	N/A	N/A	N/A	N/A	✗	✓	✗	✓	✗	✗	—
IE	187.000	4,10%	360.000	7,69%	✓	✓	✗	✓	✗	✓	✓
IT	4.035.000	7,00%	9.847.980	16,20%	✓	✗	✓	✓	✗	✓	✓ Regional level
LV	N/A	N/A	N/A	N/A	✗	✗	✗	✗	✗	✗	—
LT	N/A	N/A	N/A	N/A	✗	✗	✓	✓	✗	✓	—
LU	4.752	1,00%	N/A	N/A	✓	✗	✓	✓	✓	✓	✓ local level
MT	N/A	N/A	N/A	N/A	✗	✗	✓	✓	✓	✓	✓ local level
NL	3.500.000	21,30%	1.923.180	11,40%	✓	✓ local level	✓	✓ local level	✗	✗	✓ local level
PL	1.214.000	3,20%	3.915.030	10,30%	✗	✗	✓	✓	✗	✗	—
PT	N/A	N/A	N/A	N/A	✗	✗	✓ Regional level	✓	✗	✗	—
RO	N/A	N/A	N/A	N/A	✗	✗	✓	✓	✗	✗	—
SK	58.000	1,10%	N/A	N/A	✗	✓	✓	✓	✗	✗	—
SI	N/A	N/A	N/A	N/A	✗	✗	✗	✓	✗	✓	—
ES	427.000	0,9%	7.155.810	15,3%	✗	✗	✓	✓	✗	✗	—
SE	200.000	2,2%	750.240	8%	✓	✓	✓	✗	✓	✗	—
CH	N/A	N/A	1.047.168	10,8%	—	—	—	—	—	—	—
UK	5.550.000	8,9%	9.820.720	15,2%	✓	✓ local level	✓	✓ local level	✗	✓	✓ local level

Counsel- ling	Respite care	Training	Self-help groups
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✓	✓	✓	✗
✓ Regional and local level	✓ Regional and local level	✓ Regional and local level	✗
✗	✓	✓	✗
✗	✓	✗	✗
✗	✗	✗	✗
✓	✓ Regional and local level	✓	✓
✗	✓	✓	✗
✓	✓	✓	✓ local level
✓	✓	✓	✓ local level
✓	✓ local level	✓ local level	✓ local level
✓	✓ local level	✓	✓ local level
✓ local level	✓	✓ local level	✗
✗	✓	✗	✗
✓ local level	✓ Regional and local level	✓ local level	✓ local level
✓ Regional and local level	✓	✓	✓ Regional and local level
✓	✓	✓	✓
✗	✗	✓	✗
✓	✓	✓	✓
✗	✓	✗	✗
✓ local level	✓	✓ local level	✓ local level
✗	✗	✗	✗
✗	✓	✓	✓ local level
✗	✗	✓	✗
✗	✓	✗	✗
✗	✗	✗	✓ local level
✓	✓	✓	✓ local level
✓	✓	✗	✓
—	—	—	—
✓ Regional and local level	✓	✓ local level	✓ local level

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