

Fact Sheet



European Cancer
Patient Coalition



Developed with the support of the European Academy of Dermatology and Venereology Taskforces on NMSC and Occupational Skin Disease

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What is Non-Melanoma Skin Cancer?

Non-Melanoma Skin Cancer (NMSC) refers to all types of cancer of the skin that are not melanoma – cutaneous squamous cell carcinoma (cSCC) and cutaneous basal cell carcinoma (cBCC) being the most common – and frequently results in chronic illness due to recurring lesions in sun-exposed skin, requiring almost continuous treatment efforts.¹

With 7-8 million new cases diagnosed each year, NMSC is the most frequently diagnosed cancer in the world.^{2,3}



Quality-of-life of the NMSC patient

NMSC takes a toll on the patient's and their carer's quality-of-life. As NMSC patients potentially undergo repeated rounds of surgery, they can suffer significant physical, psychological and emotional consequences.⁴

NMSC can be associated with high morbidity, characterized by bleeding, itching, painful non-healing lesions, and reduced quality of life.^{5,6,7,8} Extensive surgical margins may be needed to remove the tumour, which can be particularly distressing for patients with facial lesions; cosmetic reconstruction may also be required.⁹ Its visible and destructive nature causes a significant burden on the physical, psychological, social, emotional and daily function domains of the patient.¹⁰

From a psychological point of view, burdens include depression, anxiety and social isolation, low self-esteem and shame, which may make it harder to find or maintain employment and provide care for dependents.¹¹



Caring for someone with NMSC

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.¹²

Carers are often partners, family members, friends or neighbours. These carers are currently providing around 80% of care across the EU.¹³ A typical carer is a woman between 45 and 75 years of age¹⁴ 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.¹⁵ And while people with cancer are identified through diagnosis, cancer carers often remain largely anonymous despite the fundamental role they play in the healthcare pathway.

Some of the tasks performed by carers of NMSC patients include:¹⁶

- 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

Psychological burden of carers

The quality-of-life of carers who support NMSC patients has the potential of being adversely affected, and the psychological burden of the patient can sometimes transfer to the carer. 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.¹⁷

Cancer carers are known to have high needs and psychological morbidity¹⁸ as they are often required to assume numerous roles and make many disruptive changes in their own lives. By being practically and emotionally involved, carers' 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. When surveyed, cancer patients and their carers¹⁹ have reported:



emotional distress such as anxiety, depression and somatization;



unmet supportive care needs; and



cancer-specific distress.

*Carers have **higher distress ratings and intrusive thinking** compared to people with cancer.²⁰*

Socio-economic burden of carers

As informal care is not remunerated and might also result in loss of working days,²¹ these socio-economic difficulties, in addition to daily caregiving tasks and duties, also significantly affect carers' quality-of-life, which only adds to their emotional distress. According to a 2009 analysis, productivity losses and loss of working days cost European families €42.6 billion and €9.43 billion, respectively.²²

Moreover, since caregiving is not considered a state of 'employment,' carers may not be able to receive health insurance. Such health insurance is essential in providing carers with the psychological and physical health support that is often needed when caring for loved ones.²³

Finally, carers may often be negatively impacted by their choice to provide care when it comes to receiving pensions.²⁴ 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.

Common challenges that carers face

1 Self-identification as a carer

In some European countries, only around 2 out of 5 cancer carers identify with the term 'carer'.²⁵ The lack of a defined group presents a monumental challenge in developing appropriate policies for carers.

2 Compensation and support

Caregiving represents an enormous cost saving to health systems,²⁶ but the growing burden of diseases means that, without appropriate compensation and support for carers, this structure of care risks collapsing.

3 Gender issues

Gender inequality in the carer population leads to disenfranchisement of women in the workplace as the burden of care prevents them from taking certain working opportunities.

4 Financial toxicity

Caregiving is associated with a significant reduction in employment and hours of work, as well as extra out of pocket costs, beyond work income loss.

5 Lack of information

7 EEA Member States²⁷ do not offer training for carers, meaning that carers either risk providing care, which may result in adverse consequences for the patient or themselves

6 Impact on physical 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.



Policy recommendations

To develop effective policies for these carers, policymakers must look beyond traditional healthcare pathways and employment policies, and acknowledge that carers continue to provide a substantial portion of care across Europe.⁹



Initiate carer identification programmes

Where possible, to support carers in their role, Government-sponsored and supported information campaigns should be initiated.



Adopt a minimum of 5 days of paid carer leave

The European Commission's proposal of 5 days per year should be supported as a baseline for long-term carers.



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 workplace and retaining staff.



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 have the opportunity to 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:

- 1) training and knowledge support for carers;
- 2) psychological support; and
- 3) integration of carers into the healthcare team.



Entitle carers to receive a retroactive pension for the years their caregiving was deemed ineligible.

Carers may often be negatively impacted by their choice to provide care when it comes to receiving pensions. 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.

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