NON-MELANOMA SKIN CANCER

Key Information and Policy Recommendations for Carers

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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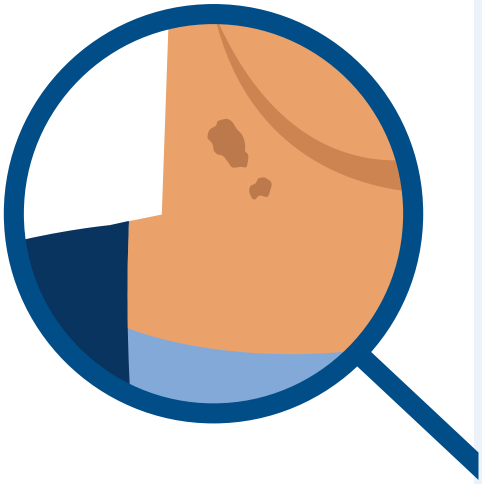
What is Non-Melanoma Skin Cancer?

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), including advanced forms of these cancer types, 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]



Prevention

Exposure to ultraviolet (UV) radiation is the most important external risk factor for the development of NMSC, and vulnerable groups such as children and outdoor workers are at a higher risk of acquiring NMSC.[4]

To prevent the development of skin cancer, it is best to adhere to the following protective measures[5]:

1. **Avoid the sun**
2. **Wear sun protective clothing**
3. **Wear a hat**
4. **Use sunglasses**
5. **Use protective sunscreen on the remaining skin areas**

Quality-of-life of the NMSC patient

From a psychological point of view, burdens include depression, anxiety and social isolation stigmatisation, low self-esteem and shame, which may make it harder to find or maintain employment and provide care for dependents.[6]

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.[7]

Carers are often partners, family members, friends or neighbours. These carers are currently providing around 80% of care across the EU.[8] A typical carer is a woman between 45 and 75 years of age.[9]

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 carers[10] have reported:

- emotional distress such as anxiety, depression and somatization;
- unmet supportive care needs; and
- cancer-specific distress.

Socio-economic burden of carers

As informal care is not remunerated and might also result in loss of working days,[11] 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 an analysis, productivity losses and loss of working days cost European families €42.6 billion and €9.43 billion, respectively.[12]

Common challenges that carers face

Self-identification as a carer

In some European countries, only around 2 out of 5 cancer carers identify with the term 'carer',[13] meaning the burden of care is underreported' after 'carer'

Compensation and support

Caregiving represents an enormous cost saving to health systems,[14] but without appropriate compensation and support for carers, this structure of care risks collapsing.

Gender issues

Gender bias in the carer population leads to disenfranchisement of women in the job market.

Financial toxicity

Caregiving is associated with a significant reduction in employment, as well as extra out of pocket costs.

Lack of information

7 EEA Member States[15] do not offer training for carers, which may result in adverse consequences for the patient or themselves.

Impact on physical and emotional health

The psychological burden on carers is immense, including financial pressures and the burden of those they are caring for.

*Carers have **higher distress ratings and intrusive thinking** compared to people with cancer.[16]*

Policy recommendations for NMSC carers

To develop effective policies and training on prevention, treatment and access to clinical information 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.[17]

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

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

Entitle carers access to appropriate health services and insurance

Considering the burden placed on many carers, foreseeing the need for additional health services is essential

Introduce a robust carer support programme

Considering the burden placed on many carers, foreseeing the need for additional health services is essential

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

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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