



# 5th LuCE REPORT ON LUNG CANCER

## Psychological and social impact of lung cancer

### · Executive Summary ·

#### | Background

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Lung Cancer Europe (LuCE) is the voice of people impacted by lung cancer, striving to make this disease an EU health priority. LuCE promotes a patient-centered and multidisciplinary approach to healthcare delivery across the entire lung cancer pathway.

This fifth report is a descriptive social research analysis exploring the major emotional and social (psychosocial) issues experienced by people impacted by lung cancer in Europe.

The findings of this report stress the need to implement a more friendly, more accessible, and more holistic approach to healthcare services and the delivery of same.

#### | Survey Participants

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The survey was completed by 559 people: 365 people with lung cancer (65.3%) and 194 caregivers (34.7%) across 17 European countries. Most of the participants were female (75.4%), and in the 55-64 age bracket (39.7%). Over half the respondents came from France (22%), Spain (11.3%), Denmark (10.9%) and Italy (10.0%).

Adenocarcinoma was the most common diagnosis (59.9%), with 49.2% diagnosed with Stage IV disease. Approximately half of those with lung cancer (47.8%) stated that they had received treatment, but their disease was still present, and just over a third were diagnosed between 1-3 years ago.

The majority of caregivers were providing care for those diagnosed with Stage IV disease (57.2%), diagnosed within the last 1-3 years (40.4%). Most were helping loved ones who had received treatment, but the disease was still present at the time of completing this survey (47.4%).





## Psychological Impact

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77.2% of caregivers and 52.5% of people with lung cancer stated that their emotional wellbeing had been negatively affected by 'quite a bit/very much'. For both, the feelings that deeply impacted their quality of life were uncertainty (62.5%), sadness (61.2%), anxiety (69.6%) and fear (59.6%).

Worries among people with lung cancer concerned the impact on their family and relatives, disease progression and death. Caregivers mainly experienced concerns about their loved one's death, disease progression as well their pain and suffering. The rate of diagnosed depression was higher in patients (18.4%) than caregivers (7.8%) surveyed. While, not having been diagnosed with depression, 20.3% of caregivers and 14.3% of people with lung cancer thought that they were depressed.

## Impact on Daily Life

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Symptoms and adverse side effects are some of the main reasons why engagement in daily and leisure activities is lower. Most people with lung cancer reported impairments in physical and role functioning, fatigue, breathlessness, and pain, which affected their wellbeing.

38.0% stated that there had been a negative impact on their household's financial situation with less income reported by 82.1% of respondents. At the same time, 38.1% of people surveyed reported a negative impact on the work situation of someone in their house as well, mainly due to the inability to work (55.7%), time off work (23.2%) and the need to opt for early retirement (21.2%).

Lung cancer can also impact family dynamics and routines - 7 out of 10 acknowledged that they needed to make some changes in their family life after diagnosis. These changes mainly related to daily routines, less social and family interaction, changes of plans and new healthy habits.

## Supportive Care

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The key unmet needs reported by participants were psychological needs (41.4%), symptom control and management (40.7%), impact on family (32.5%) as well as rehabilitation and exercise (30.6%).

The professionals most needed by people with lung cancer were nutritionists (24.3%), psychologists (20.2%) and physiotherapists (17.8%). Meanwhile, caregivers stated that they would need help from psychologists (41.7%), nutritionists (30.4%) and social workers (23.5%).

34.9% of those surveyed received some support from a patient organisation or a non-governmental organisation (NGO). The factors that were more useful for people who received this kind of support was information about the disease and treatments, and the contact with other people impacted by the disease. This 'peer to peer' support can positively impact quality of life. Most people surveyed were satisfied with the support received by their family, and this satisfaction was higher among patients than caregivers.

In terms of the level of satisfaction with support received to help with daily chores, 61.2% of patients *'did not have anyone/had help only some of the time'*. There was also a lack of emotional support for patients - 21.9% felt they could not count on anyone to receive this support *'ever or only a little of the time'*, and 20.3% only *'some of the time'*. For caregivers, 22.3% did not have anyone around to help with daily chores and 30.9% could not count on anyone for emotional support for *'none of the time/ a little of the time'*.





## Stigma

The stigma associated with lung cancer greatly affects people impacted by this disease. More than 80% pointed out that people asked them about their smoking history when they learned about their lung cancer diagnosis. Participants also confirmed some stigmatizing attitudes and behaviours from others, such as considering the person as responsible for getting lung cancer (reported by 30.9% of patients and 41.2% of caregivers) or judging the person negatively for having this disease (reported by 28.2% of patients; 24.0% of caregivers).

Internalised stigma is also a major issue with 66.8% of patients stating that they had thought at times that their previous behaviour had contributed to their diagnosis. 52.4% had at times felt guilty because of their diagnosis, with nearly 2 in every 10 indicating that they felt this way frequently. Caregivers also experienced stigma and self-blame, with 37.1% acknowledging having feelings of guilt.

## Call to action

- **Provide integrated psychosocial services in the lung cancer care pathway**

Improve quality of life for people impacted by lung cancer by delivering access to appropriate psychological and social services throughout the entire care pathway; tackle stigma through improved communication skills.

- **Increase awareness of patient organisations and NGOs**

Encourage health services to signpost people impacted by this disease to patient organisations, NGOs and support centres; provide training to increase the number of people able to offer 'peer to peer' support.

### Full Report

Access the full 5th LuCE Report 'Psychological and social impact of lung cancer is available here: <https://www.lungcancereurope.eu/2020/10/15/5th-edition-of-the-luce-report/>

Get in touch: