Lung Cancer Europe

· 2021 ·

6th LuCE Report on lung cancer

Experiences and quality of life of people impacted by lung cancer in Europe

· Executive Summary ·

Background

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 person-centered and multidisciplinary approach to healthcare delivery across the entire lung cancer pathway.

This sixth report is a descriptive research analysis that explores the experiences of people impacted by lung cancer in Europe along their disease journey. Data was collected through a self-filled online survey and was open to both people with lung cancer and those in a caregiving capacity.

Survey Participants

The survey was completed by 800 people: 515 people with lung cancer (64.4%) and 285 caregivers (35.6%) across 21 European countries.

- **People with lung cancer: characteristics**

  The majority were women (74.8%) between 55-64 years of age (40.2%). 75.6% were diagnosed with `non-small cell lung cancer – adenocarcinoma´ and 68.2% confirmed that their tumor was positive for a molecular marker. 59.9% had Stage IV disease and 67.5% of participants were on active treatment at the time of completing this survey.

- **Caregivers: characteristics**

  Most of the participants were women (80.7%) between 35-40 years of age (30.2%). 85.6% of participants were the primary caregiver with 34.4% stating that they were the only caregiver. Around half of caregivers (51.6%) stated that their loved one had Stage IV disease.

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Results: people diagnosed with lung cancer

Daily activities: A total of 91.2% of participants experienced some limitations in daily activities. The impact on daily life was especially severe for 1 out of 4 participants, which was linked to fatigue (70.9%), breathlessness (42.8%) and emotional issues (39.4%).

One-third experienced significant changes in their ability to shop, climb stairs and walk for longer than 15 minutes. Thus, 48.0% of respondents acknowledged needing assistance to perform at least one daily activity (sometimes-often-always).

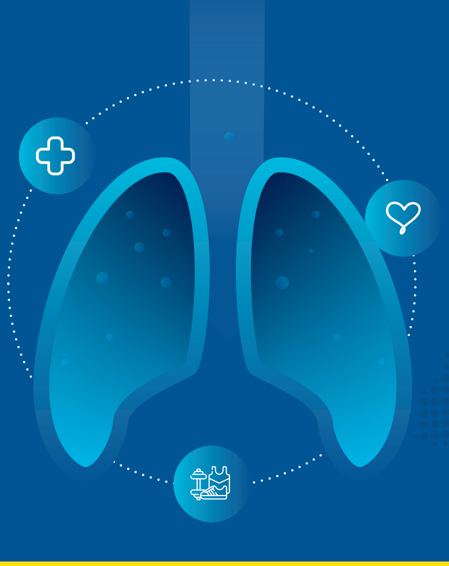
Symptoms and side effects: The most common symptoms and side effects reported by survey participants were fatigue (92.8%), sleep disturbances (78.3%), weight changes (76.6%), breathing difficulties (75.7%) and digestive disorders (75.0%). We found that fatigue (45.3%), weight changes (31.7%), sleep disturbances (29.0%), digestive disorders (28.5%) and sexual issues (24.9%) were the effects that most impacted participants' QoL and well-being.

Quality of life (QoL): Participants reported some factors that negatively impacted their QoL:

- 78.3% reported sleep problems mainly due to worries and intrusive thoughts (60.5%), nocturia (28.4%) and pain/discomfort (27.9%).
- 77.0% experienced problems with memory, concentration or their thought process, which they felt interfered with their daily life.
- 55.1% reduced their physical activity level since diagnosis. This was mainly due to fatigue and breathlessness.
- 49.5% reported eating difficulties, highlighting dry mouth (21.3%), taste or smell changes (20.4%) and appetite loss (19.7%).
- 24.9% reported a severe impact on sexual relationships. Fatigue was reported as the main reason for the deterioration of their sexual life (37.1%), followed by emotional issues (36.8%) and body changes (30.1%).

Support: Most participants (64.6%) were satisfied with the support they received. However, 52.8% did not feel equipped to self-manage their symptoms and side effects. In addition, only 59.7% of participants felt they received all the information they required (quite a bit-very much). On the other hand, less than half of respondents (45.7%) always reported symptoms and side effects to their healthcare providers.

Decision involvement and healthcare: 1 in 4 had little to no involvement in their healthcare decisions, and 1 out of 5 felt that their opinion was never or rarely considered. However, the majority of participants showed satisfaction regarding the healthcare they received: 68.1% reported rapid access to specialists and 70.9% felt that their healthcare team were able to coordinate their disease journey. However, our report findings show an urgent need to improve communication regarding end-of-life care. It is particularly significant that 1 out of 3 participants (32.2%) had not discussed end-of-life care, even though they would have liked to.



RESULTS: people caring for someone with lung cancer

Daily activities: A total of 88.6% of participants acknowledged some limitations in daily life related to caregiving. Main reasons for this were their own emotional concerns (63.1%), treatment requirements (54.1%) and caregiving responsibilities (49.1%).

Stress: 79.4% stated that they spent a lot of time thinking about the disease and 65.9% acknowledged feeling that their life was dominated by treatment and test results. Issues contributing to stress included dealing with declining health (70.6%) and providing emotional support (69.8%) to the person diagnosed with the disease.

Self-care: Participants experienced some difficulties in balancing caregiving responsibilities:

- 82.3% reported some physical health deterioration since they started caregiving. The two physical problems that most impacted participants were sleep disturbances (94.7%) and fatigue (91.1%).
- 53.7% had reduced their physical activity, primarily due to their emotional situation (59.5%) and fatigue (53.2%).
- 51.8% stated that they did not self-care at all or just a little bit.
- 46.2% felt that they didn´t have time for themselves.
- 36.9% acknowledged that they have not attended all their own medical appointments.

Support: Caregiving requires supporting many different issues and being involved in the disease journey: offering emotional support (88.5%), attending medical appointments (83.4%), helping with care and treatment decisions (74.3%) and doing housework and shopping (73.9%), among other things. However, only 1 out of 3 participants (32.5%) felt supported in their role as caregivers.

Few (11.5%) said they received support from healthcare professionals in delivering the best care possible to their loved one. Thus, more than half (56.2%) reported that they did not receive any support to maintain and improve their own health and QoL. The most frequent support need was psychological counselling (51.9%).

Role in treatment decisions: Eight out of 10 were directly involved in treatment decisions and 32.2% stated they were the primary decision-maker. Communication between people living with lung cancer, caregivers and the care team are crucial. However, 44.3% of caregivers guarded medical information to protect their loved one.

End-of-life care: For those whose loved one had passed away (n=71), main difficulties identified were patient symptom management (77.9%), how to best offer emotional support (76.5%) and how to offer best care (76.5%). 40.6% were not satisfied with the discussions they had with their loved one about end-of-life decisions.

For those still actively caregiving (n=127), 50.0% of participants confirmed that they discussed end of life care with their loved one. However, half considered that they had not discussed it enough, and we identified a further 9.5% who had not talked about end of life, although they would have liked to.

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Call to action

- Ensure access to supports to help with the impact of lung cancer and treatment.
- Develop care plans and educational programmes with the aim to improve quality of life for people impacted by lung cancer.
- Develop better communication between people impacted by lung cancer and healthcare professionals.
- Raise awareness and develop communication support concerning end-of-life care.

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Get in touch:

Lung Cancer Europe

Many faces, One voice

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