October 2025

10th LuCE REPORT ON LUNG CANCER

LUNG CANCER AND MENTAL HEALTH

Experiences reported by Europeans impacted by lung cancer

LuCE

Lung Cancer Europe

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All the Report materials are accessible here:

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Lung Cancer Europe

Mental health is a vital part of the care journey after diagnosis.

That is why Lung Cancer Europe (LuCE) has devoted this 10th Report to this important topic.

We extend our heartfelt thanks to all the organisations and individuals who have contributed to this initiative. Together, we will raise awareness and work together to implement meaningful solutions.

We are especially grateful to the 2,204 individuals who generously shared their experiences by taking part in our survey.

Your voices are at the heart of this report, and your experiences help drive the change we all seek.

Lung cancer affects far more than just the lungs—it reaches deep into the emotional and psychological lives of those impacted. For too long, this subject has been overlooked or underestimated. This 10th LuCE Report marks a turning point. It elevates the voices of over **2,204 individuals**—making it the **largest global survey ever conducted** on the mental health experiences of people living with, or caring for someone with, lung cancer.

Their testimonies are striking. Nearly half of respondents reported that emotional difficulties frequently or constantly disrupted their daily lives. Over 40% did not feel equipped to cope with the psychological toll of the disease. These findings reveal not just gaps in support, but a pressing call for change.

Mental health is not a side issue—it is a central pillar of cancer care. This report urges healthcare systems, clinicians, and policymakers to take action: to ensure psychological support is woven into every step of the lung cancer journey, from diagnosis to survivorship.

To every patient and caregiver who shared their story—thank you. **Your stories transform this research into a roadmap for progress, and for hope.**

Debra Montague

President of Lung Cancer Europe (LuCE)

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1. ABOUT THIS REPORT

Description

Lung Cancer Europe (LuCE) is an independent non-profit organisation, committed to making lung cancer a European healthcare priority. LuCE, as the voice of Europeans impacted by or at risk of lung cancer, works to ensure that people living with this disease get the care they need to achieve the best possible outcomes.

LuCE recognises the important benefits of building evidence for the entire lung cancer community. That is why we conduct annual research to explore the needs and experiences of people impacted by lung cancer and to raise awareness about the challenges our community faces.

This 10th report titled **`Lung cancer and mental health: Experiences reported by Europeans impacted by lung cancer´** is a descriptive research analysis that explores the psychological impact of lung cancer and aims to better understand the mental health experiences of people impacted by this disease across Europe.

All the Report materials are accessible here:

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Previous reports have highlighted the psychological impact and mental health challenges experienced by people with lung cancer. LuCE is deeply committed to this topic, given its significant influence on the overall well-being of those living with lung cancer. Therefore, this survey aims to further explore these issues and provide valuable insights to better support the lung cancer community.

Objectives

- To explore the emotional and mental health challenges faced by individuals impacted by lung cancer
- To identify the key stressors and emotional issues experienced
- To assess the availability, accessibility, and effectiveness of mental health support services for people impacted by lung cancer
- To gather perspectives on unmet emotional needs and opportunities for improving psychosocial support

Methodology

The primary data collection method used in this research was an online survey designed to explore the mental health, psychological, and care-related needs of individuals impacted by lung cancer, including both people with the disease and their loved ones. This method was chosen for its capacity to reach a wide and diverse population regardless of geographic location, and because it ensures anonymity. By protecting privacy, participants may feel more comfortable sharing personal or sensitive information. In contrast, online surveys do give rise to some limitations. There are difficulties to reach some participants, such as those who do not have internet access, are not regular internet users, are not digitally literate or have a poor health status to complete an online survey.

The following section describes how the project was designed, how data were collected and analysed, and how the results were reported.

February - March 2025

LITERATURE REVIEW

- To inform the design of the survey, a structured literature review was conducted using online scientific databases
- The search strategy focused on identifying existing studies, reports and guides about mental health, psychological repercussions, supportive care and quality of life in the context of lung cancer
- Only publications available in the English language were included in the review
- References are provided at the end of this report

March – May 2025

ONLINE SURVEY DESIGN

- The survey was designed by MÁS QUE IDEAS Foundation and reviewed by the LuCE Report Working Group

- It was designed to be user-friendly and easily accessible, allowing respondents to complete it at their own convenience. Most questions were optional, with only filter questions requiring a response. As a result, the response counts vary from question to question.
- No questions relating to personal information were included to ensure anonymity
- The survey covered 43 closed-ended and three open-ended questions to capture both quantitative and qualitative insights
- The survey was translated into 19 languages: Bulgarian, Croatian, Danish, Dutch, English, Finnish, French, German, Greek, Hebrew, Hungarian, Italian, Latvian, Polish, Portuguese, Romanian, Slovenian, Spanish and Ukrainian. The translations were reviewed by LuCE members to ensure the quality of the translated material.

May - July 2025

ONLINE SURVEY DISSEMINATION

- Self-filled online survey via the SurveyMonkey® platform
- It was disseminated through the communication channels of LuCE and its members
- The survey was active from May 28th until July 6th, 2025
- Number of responses: 2,204 (1,709 people with lung cancer and 495 caregivers)

July - October 2025

DATA ANALYSIS

- A quality control check of the data was performed to identify and remove responses from outside the WHO European region and incomplete surveys. A survey was considered valid when the participant had completed, at least, the first two series of questions (25 questions).
- For the analysis of the results, the statistical tools provided by SurveyMonkey® were used, along with Jamovi software®, which enabled the performance of independent samples t-tests. These tests help determine whether there are statistically significant differences between the means of two independent groups*. Additionally, artificial intelligence (ChatGPT®) was used as a complementary tool to support the interpretation of correlations and statistical outputs, as well as for data analysis and reporting.
- All data were combined to create a draft of this report, which was reviewed and finalised by the LuCE Report Working Group

Main characteristics of participants

The total number of survey participants was 2,204. This consisted of 1,709 people diagnosed with lung cancer (77.54%) and 495 caregivers** (22.46%) from 31 WHO European Region countries. The majority of participants were women (78.35%), and the most common age group was 55 to 64 years (35.89%). A total of 70.36% were diagnosed (or their loved one) with non-small cell lung cancer (NSCLC) – adenocarcinoma. Additionally, 56.20% had (or their loved one) Stage IV disease, and for 63.71% of all participants the diagnosis occurred less than three years prior to the survey.

A brief snapshot of the participant characteristics is provided below (Tables 1 and 2). Complete survey participant characteristics are provided in Annex I.

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* Groups analysed: patients vs. caregivers; women vs. men; early stage (I-II) vs. advanced stage (III-IV); younger adults (18-64) vs. older adults (65+).

** For the purpose of this report, the term `caregiver´ refers to informal caregivers: people caring for someone with lung cancer, as family, friends or partners (not healthcare professionals).

Main sociodemographic characteristics of participants

	Total		People with lung cancer		Caregivers	
GENDER	**Women** **Men**	78.35% 21.01%	**Women** **Men**	77.29% 22.29%	**Women** **Men**	82.00% 16.56%
AGE	**45 - 54** **55 - 64** **65 - 74**	21.71% 35.89% 24.23%	**45 - 54** **55 - 64** **65 - 74**	20.32% 39.10% 27.13%	**45 - 54** **55 - 64** **65 - 74**	26.48% 24.85% 14.26%
COUNTRY	**France** **UK** **Netherlands**	17.20% 16.97% 11.25%	**France** **UK** **Netherlands**	20.89% 18.43% 12.35%	**Greece** **UK** **Ukraine**	17.37% 11.92% 10.91%
EDUCATION	**Upper secondary** **Tertiary education**	35.66% 57.12%	**Upper secondary** **Tertiary education**	37.05% 55.23%	**Upper secondary** **Tertiary education**	30.89% 63.62%

Table 1. *Sociodemographic characteristics of participants.*

Disease characteristics of participants

	Total		People with lung cancer		Caregivers	
TYPE OF LUNG CANCER	**NSCLC (Adeno-carcinoma)**	70.36%	**NSCLC (Adeno-carcinoma)**	75.09%	**NSCLC (Adeno-carcinoma)**	54.08%
BIOMARKER	**EGFR**	23.47%	**EGFR**	25.97%	**I don´t know**	29.04%
	ALK	21.76%	**ALK**	22.50%	**ALK**	19.22%
	I don´t know	21.11%	**I don´t know**	18.79%	**EGFR**	14.93%
STAGE	**Stage I -II**	25.55%	**Stage I -II**	28.23%	**Stage I -II**	16.33%
	Stage III	16.68%	**Stage III**	16.25%	**Stage III**	18.16%
	Stage IV	56.20%	**Stage IV**	53.86%	**Stage IV**	64.29%
TIME SINCE DIAGNOSIS	**Less than 1 year**	24.52%	**Less than 1 year**	21.93%	**Less than 1 year**	33.47%
	1 to 3 years	36.19%	**1 to 3 years**	35.51%	**1 to 3 years**	38.54%
	3 to 5 years	19.05%	**3 to 5 years**	20.58%	**3 to 5 years**	13.79%
	5 years or more	20.24%	**5 years or more**	21.99%	**5 years or more**	14.20%

Table 2. *Disease characteristics of participants.*

2. KEY FINDINGS

1

The mental health impact of lung cancer was profound.

- Most participants (61.16%) reported a significant negative impact on their mental health following a lung cancer diagnosis, rating it between 1 and 5 on a scale where 1 was `very negative´ and 10 `very positive´.

- Caregivers, individuals impacted by advanced-stage lung cancer (Stage III-IV), and younger participants (aged 18-64)* reported significantly worse outcomes in terms of mental health.

2

Sadness, fear, anxiety, and uncertainty were the main emotions reported.

- Over half of respondents identified these four emotions as deeply affecting their quality of life: sadness (58.54%), fear (56.49%), anxiety (56.31%), and uncertainty (55.22%). Caregivers more frequently reported experiencing emotions that had a strong impact on their lives, especially sadness (75.10%) and fear (74.70%).

- Fear of treatment failure or cancer progression was the most common emotional difficulty, affecting 76.71% of participants. Other frequent fears included side effects (52.32%), suffering (45.27%), and death (44.27%).

- Sadness was another frequently reported emotion, due to the impact on the lives of loved ones (57.64%) and the impact of lung cancer on their own lives (44.36%).

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*To facilitate age-related comparisons, participants were categorized into two groups: those aged 65 and older (30.56%) and those younger than 65. Within the younger group, the majority were between 45 and 64 years of age (57.60%).

3

Diagnostic-related issues and side effects were the most emotionally distressing parts of the care journey.

- A lung cancer diagnosis was cited as a major source of emotional distress (63.62%). Other significant diagnostic-related stressors included receiving additional news beyond the diagnosis (e.g., prognosis and stage of cancer) (39.61%) and the diagnostic process itself (32.47%).

- Additionally, managing physical symptoms and side effects was reported by 45.52% of participants as a key contributor to emotional strain.

4

Emotional difficulties frequently disrupted daily life.

- Nine out of ten participants experienced emotional difficulties that affected their daily lives following a lung cancer diagnosis. Nearly half (46.31%) reported that these emotional challenges often or constantly interfered with their daily functioning.

- The impact was significantly greater among caregivers, women, and younger individuals (aged 18-64).

- Social life and lifestyle were the areas most affected by participants' mental health, with 48% reporting a high impact.

- Finances and work-related aspects were also notably impacted: three out of four respondents (77.24%) reported some degree of impact, and more than 44.91% said they were highly affected.

5

Half of the participants felt unable to manage their lives and the emotional impact of lung cancer.

- A considerable 45.19% reported experiencing emotional struggles after the diagnosis and feeling incapable of dealing with all the issues in their lives, with caregivers and younger participants (aged 18–64) being particularly affected.

- Similarly, 44.53% stated they did not feel well equipped to cope with the emotional repercussions of the disease. Women felt less capable than men, and younger participants (aged 18-64) were less likely to feel emotionally prepared compared to older adults (aged over 64).

6

Depression and anxiety disorder were significant psychological comorbidities for people impacted by lung cancer.

- Depression was diagnosed in 1 in 4 participants, and anxiety in 1 in 5. In both cases, many diagnoses occurred prior to the lung cancer diagnosis. Women, individuals with advanced-stage lung cancer (Stage III or IV), and younger adults (aged 18–64) were significantly more likely to report an anxiety disorder diagnosis.

- Only about 6 in 10 participants who experienced depression or an anxiety disorder after the diagnosis of lung cancer expressed satisfaction with the treatment received for their mental health disorder.

- Notably, among those without a formal diagnosis (without a diagnosis of depression: 1,533; without a diagnosis of anxiety disorder: 1,617), a significant proportion believed they had depression (15.18%) or an anxiety disorder (15.55%).

- Worryingly, 43.97% reported experiencing extreme sadness, 24.68% felt trapped, and 21.16% had persistent feelings of hopelessness or worthlessness since their diagnosis.

7

Living normally, a healthy lifestyle, and support from loved ones were key to maintaining good mental health after diagnosis.

- Maintaining a sense of normality was the most frequently cited factor influencing mental health (53.29%). Additionally, 49.45% of participants reported that adopting a healthy lifestyle contributed to their mental well-being, followed by 45.47% who found support from loved ones helpful.

- Individuals diagnosed with lung cancer reported using a wider range of coping strategies than caregivers to maintain their mental health.

8

Emotional support from family and friends played a central role in coping with lung cancer, but challenges remained.

- A total of 82.51% were satisfied with the support received from their loved ones, identifying this as the most rewarding aspect since the diagnosis. However, only 58.91% reported always having someone to help when needed, and nearly 1 in 4 said they rarely or never shared their emotions with those around them.

- The main challenge cited regarding the support received was that people close to them did not fully understand what they were going through (65.54%).

9

Mental health support remained limited and inconsistently addressed along the care pathway.

- Half of the respondents were not offered any form of mental health support. Additionally, almost 4 in 10 participants experienced emotional difficulties but did not report them to their healthcare team. Women, individuals with advanced-stage lung cancer (Stage III-IV), and older adults (over 64) were more likely to report emotional difficulties.

- Two key healthcare challenges emerged: most participants (65.88%) were not informed about patient support groups or non-profit organisations, and 41.34% felt that their healthcare team had not provided adequate emotional support.

10

Measures proposed to improve mental health: medical information and support with side effects.

- Half of the participants indicated that having more information about the disease, treatment, and care options were the most important measures to improve mental health. Support in managing side effects was also cited by 43.90% of respondents, while improving communication with healthcare professionals (37.59%) and enhancing access to mental health services (34.36%) were other key suggestions.

3. RESULTS

3.1. THE HUMAN SIDE OF LUNG CANCER: A CLOSER LOOK AT MENTAL HEALTH

Lung cancer is associated with higher disease burden, more physical hardships, and greater symptom distress than other cancer types[1], making it the most physically and emotionally challenging among all cancers[2].

> *1 in 4 participants rated their mental health as low to moderate.*

When asked to rate their mental health at the time of completing the survey, most participants described it as moderate (Table 3). On a scale from very poor (1) to excellent (10), the most frequent responses were 8 (22.49%) and 7 (19.38%). Notably, **1 in 4 participants (27.93%) reported poor to moderate mental health[*],** which highlights a significant group of individuals in a situation of psychological vulnerability.

There was a statistically significant difference in self-rated mental health between caregivers and patients with **caregivers reporting lower mental health scores than people diagnosed with lung cancer[**].** Almost half of the caregivers (45.44%) rated their mental health between 1 and 5, which was much higher than among people with lung cancer (22.82%).

Additionally, **younger participants (aged 18-64) reported significantly worse mental health** than older participants (older than 64)[***], and women reported **significantly lower mental health scores** compared to men[****]. A greater proportion of women (29.61%) reported poor to moderate mental health compared to men (20.57%), further illustrating the gender-based differences in perceived mental health status.

How would you rate your mental health today?

1 is 'very poor' and 10 is 'excellent´

	1	2	3	4	5	6	7	8	9	10
All participants (n=2,188)	**1.97%**	**2.56%**	**4.48%**	**5.94%**	**12.98%**	**12.11%**	**19.38%**	**22.49%**	**11.11%**	**6.99%**
People with lung cancer (LC) (n=1,695)	*0.71%*	*1.47%*	*3.54%*	*5.60%*	*11.50%*	*12.15%*	*19.88%*	*25.31%*	*11.86%*	*7.96%*
Caregivers (n=493)	*6.29%*	*6.29%*	*7.71%*	*7.10%*	*18.05%*	*11.97%*	*17.65%*	*12.78%*	*8.52%*	*3.65%*

Table 3. *Mental health: self-assessment*

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[*] Rate between 1 and 5 [**] $t(2186) = -11.8$, $p < .001$. Cohen's $d = -0.60$. [***] $t(2154) = -7.93$, $p < .001$. Cohen's $d = -0.37$.
[****] $t(2157) = -5.4734$, $p < .001$. Cohen's $d = -0.28$.

61.16% reported a negative impact of lung cancer on their mental health.

Previous research has shown a high incidence of psychological distress in people impacted by lung cancer, with high rates of discomfort and unpleasant experiences[3]. Our survey has identified a direct connection between lung cancer and mental health. Table 4 shows that **most participants (61.16%) reported a negative impact of lung cancer on their mental health** (rating 1-5, on a scale from 1 `very poor´ to 10 `excellent´). Surprisingly, 29.76% of respondents rated the impact of the disease on their mental health very positively (rating 7-10).

As noted, there was a statistically significant difference between caregivers and patients in terms of how they rated the impact of lung cancer on their mental health, with **worse outcomes reported by caregivers*.** Notably, 50.91% of caregivers reported a very negative impact (ratings 1–3) of lung cancer on their mental health, compared to 26.82% of patients. These results suggest that caregivers experience a greater psychological burden than patients themselves. Previous literature has shown that the impact of lung cancer on caregivers' health and well-being becomes increasingly significant as the disease advances[4].

Our findings show a significant statistical difference between respondents impacted by early-stage lung cancer (I-II) *vs.* advanced lung cancer (Stage III-IV). **Those with advanced-stage lung cancer reported a more negative impact** of the disease on their mental health compared to those with early-stage cancer**. As well, **younger people (aged 18-64) reported a higher negative impact of lung cancer on their mental health** than older individuals (older than 64)***.

How would you rate the impact of lung cancer on your mental health?

1 is 'very negative' and 10 is 'very positive´

	1	2	3	4	5	6	7	8	9	10
All participants (n=2,178)	**11.75%**	**8.54%**	**11.94%**	**10.84%**	**18.09%**	**9.09%**	**10.47%**	**10.15%**	**5.37%**	**3.76%**
People with lung cancer (LC) (n=1,689)	*9.06%*	*6.63%*	*11.13%*	*10.60%*	*19.24%*	*9.89%*	*11.84%*	*11.78%*	*6.04%*	*3.79%*
Caregivers (n=489)	*21.06%*	*15.13%*	*14.72%*	*11.66%*	*14.11%*	*6.34%*	*5.73%*	*4.50%*	*3.07%*	*3.68%*

Table 4. *Impact of lung cancer on mental health.*

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* t(2176) = -10.3, p < .001. Cohen's d = -0.53. ** t(2123) = -3.346; p < .001. Cohen's d = -0.16.
*** t(2144) = –10.11, p < .001. Cohen's d = –0.47.

In terms of emotional impact, more than half of the patients and caregivers reported the same main four main feelings that deeply affected their quality of life: **sadness, fear, anxiety** and **uncertainty.**

Table 5 highlights differences between individuals diagnosed with lung cancer and caregivers. Caregivers more frequently reported emotions that had a strong impact on their lives compared to patients, with the most notable differences observed in sadness (75.10% *vs.* 53.75%), fear (74.70% *vs.* 51.23%), anxiety (64.57% *vs.* 53.92%), anger/frustration (42.11% *vs.* 32.20%), and hopelessness (42.11% *vs.* 17.45%).

> *Fear of not being heard about my end-of-life wishes.* *(Person with lung cancer from France)*

> *Helplessness. I could help my wife, but I couldn't cure her.* *(Caregiver from The United Kingdom)*

> *Angry at the tobacco industry and the government.* *(Person with lung cancer from The Netherlands)*

> *Fear of dependence on others, fear of inability to function normally as a parent, spouse, employee.* *(Person with lung cancer from Croatia)*

> *No anger, just frustration with the fatigue side effect of medication.* *(Person with lung cancer from The United Kingdom)*

Please, select the emotions that have deeply affected your quality of life because of lung cancer

	All participants (n=2,202)	People with LC (n=1,708)	Caregivers (n=494)
Sadness	58.54%	53.75%	75.10%
Fear	56.49%	51.23%	74.70%
Anxiety	56.31%	53.92%	64.57%
Uncertainty	55.22%	53.98%	59.51%
Anger / Frustration	34.42%	32.20%	42.11%
Vulnerability	31.74%	32.55%	28.95%
Loneliness	25.75%	26.93%	21.66%
Hopelessness	22.98%	17.45%	42.11%
Reduced self-esteem	18.39%	20.20%	12.15%
Guilt	17.12%	15.81%	21.66%
Shame	6.09%	6.85%	3.44%
None	5.04%	6.32%	0.61%

Table 5. *Emotions that affected quality of life.*

Deeper analysis of the main emotional difficulties reported by participants (Table 6) reveals that **fear** was the most cited emotion, appearing in four of the six most common difficulties. **The most common fear was that the treatment may not work and/or that the cancer may progress** (76.71%), followed by fear of side effects or complications (52.32%), fear of suffering (45.27%), and fear of death (44.27%).

The most prevalent fear was that the treatment may not work and/or that the cancer may progress.

Sadness is another frequently reported emotion in our survey, **due to the impact on loved ones** (57.64%) and the **impact of lung cancer on their own lives** (44.36%).

Another relevant finding is that 1 in 4 participants highlighted feeling vulnerable due to reliance on others (30.03%), worries about changes in their jobs or finances (27.80%) and disappointment in relationships with others (25.66%).

Since the diagnosis, have you ever experienced any of the following emotional difficulties?

All participants (n=2,198)

DIFFICULTIES REPORTED BY MORE THAN 50% OF PARTICIPANTS	
76.71%	Fear that the treatment may not work and/or that the cancer may progress
57.64%	Sadness about the impact on my loved ones
52.32%	Fear of side effects or complications
DIFFICULTIES REPORTED BY 40 – 50% OF PARTICIPANTS	
45.27%	Fear of suffering
44.36%	Sadness or frustration about the impact on my life
44.27%	Fear of death
DIFFICULTIES REPORTED BY LESS THAN 40% OF PARTICIPANTS	
30.03%	Vulnerability from depending on others
27.80%	Worry about changes in my job / finances
25.66%	Disappointment in relationships with other people
22.02%	Feeling misunderstood and lonely
17.47%	Concern about the impact on my body image

Table 6. *Emotional difficulties since the diagnosis.*

Our report found **slight differences in responses between patients and loved ones** (Table 7). Caregivers reported fear more frequently than patients, particularly concerns that the treatment may not work (84.73% *vs.* 74.40%), side effects or complications (61.91% *vs.* 49.56%), suffering (53.97% *vs.* 42.77%), and death (58.66% *vs.* 40.13%).

On the other hand, patients reported greater sadness related to the impact on their loved ones (60.75% *vs.* 46.84%), a sense of vulnerability due to depending on others (32.34% *vs.* 22.00%), and concerns about their body image (19.63% *vs.* 9.98%).

Since the diagnosis, have you ever experienced any of the following emotional difficulties? *Comparison between patients and caregivers*

	People with LC (n=1,707)	Caregivers (n=491)
Fear that the treatment may not work and/or that the cancer may progress	74.40%	84.73%
Sadness about the impact on my loved ones	60.75%	46.84%
Fear of side effects or complications	49.56%	61.91%
Fear of suffering	42.77%	53.97%
Sadness or frustration about the impact on my life	44.46%	43.99%
Fear of death	40.13%	58.66%
Vulnerability from depending on others	32.34%	22.00%
Worry about changes in my job / finances	29.29%	22.61%
Disappointment in relationships with other people (family, friends, neighbours, etc.)	26.01%	24.44%
Feeling misunderstood and lonely	23.49%	16.90%
Concern about the impact on my body image	19.63%	9.98%
None	2.58%	1.02%

Table 7. *Emotional difficulties since the diagnosis (patients vs. caregivers).*

Nothing deeply affected me, but I felt uncertain by from the fact that you never know what will happen with disease progression. (Person with lung cancer from Germany)

Feeling discouraged from the side effects and the struggle to understand your body's reactions. (Person with lung cancer from The Netherlands)

How to prepare my loved ones and myself for the end, death. (Person with lung cancer from Belgium)

Cancer becoming resistant to targeted therapy, new treatments not working, health and energy declining. This has had an impact on my mental health. (Person with lung cancer from Ireland)

The fact that there is no access to euthanasia in Finland and that unbearable suffering through suffocation could lie ahead. (Person with lung cancer from Finland)

Accepting that I can't do everything I used to physically and cognitively. (Person with lung cancer from Belgium)

Confronting the possibility of death. (Caregiver from Slovenia)

An overwhelming 95.16% of survey participants said they struggled emotionally with at least one aspect of their experience. Among them, roughly half highlighted three particular challenges (Figure 1):

The most reported challenge was dealing with a life-threatening disease.

- **Dealing with a life-threatening disease** (58.60%). Table 8 shows that this percentage was 10 points higher in caregivers (67.01%) compared to patients (56.19%).
- **Difficulty of living with the uncertainty of their current situation** (53.81%). According to literature, fear and uncertainty are linked to concerns about prognosis and disease progression, often leading to feelings of being \`out of control´[5].
- **The challenge of not being able to live as they did before the diagnosis** (48.24%).

Concerns about the impact of lung cancer on their own lives and loved one´s lives were again reported by a significant percentage of participants (42.04%). This data emphasises the need for family-centred interventions to reduce or address the potential impact of the disease on patients and loved ones.

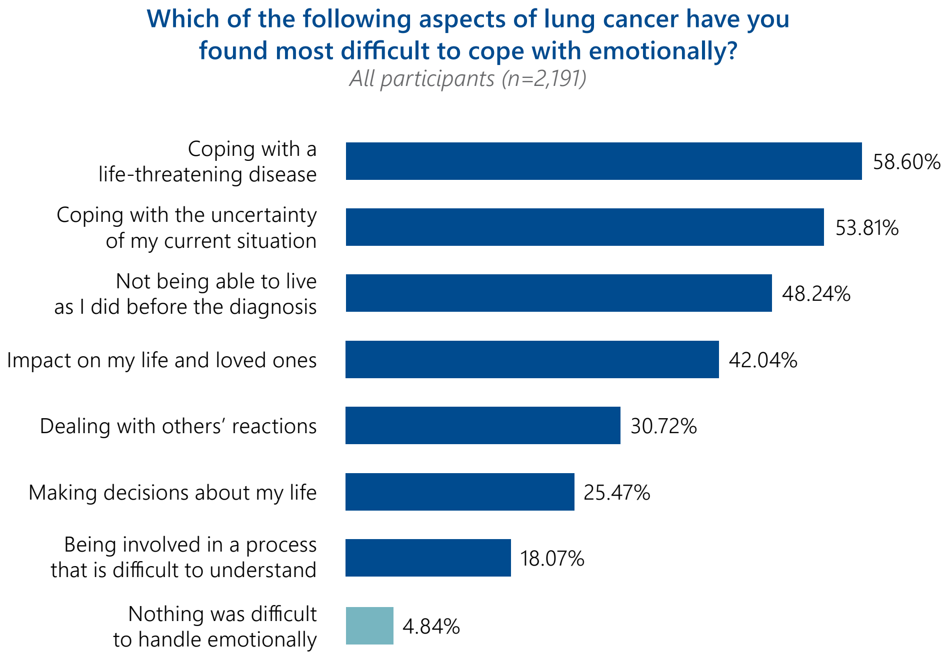

Figure 1. *Aspects of lung cancer most difficult to cope with emotionally.*

Which of the following aspects of lung cancer have you found most difficult to cope with emotionally?

Comparison between patients and caregivers

	People with LC (n=1,703)	Caregivers (n=488)
Coping with a life-threatening disease	56.19%	67.01%
Coping with the uncertainty of my current situation	52.61%	57.99%
Not being able to live as I did before the diagnosis	48.74%	46.52%
Impact on my life and loved ones	43.10%	38.32%
Dealing with others' reactions	31.65%	27.46%
Making decisions about my life	25.84%	24.18%
Being involved in a process that is difficult to understand	16.62%	23.16%
Nothing was difficult to handle emotionally	5.58%	2.25%

Table 8. *Aspects of lung cancer most difficult to cope with emotionally (patients vs. caregivers).*

After a couple of years, when the situation seemed to worsen, the pain of leaving my wife and daughters without being able to grow old with the former and see the latter become adults. (Person with lung cancer from Italy)

I can't swim, travel, drive. It's affected my self-image and mental health. The fear is not from lung cancer, but that life is again severely limited. (Person with lung cancer from The United Kingdom)

Grief over the loss of normal life. (Person with lung cancer from The Netherlands)

I can't do the things I used to do before I got sick. Wash clothes, clean, etc., without getting overwhelmed. (Person with lung cancer from Sweden)

Being aware of the limitations of the treatment and its possible loss of effectiveness at an undefined moment and trying to avoid thinking about it. (Person with lung cancer from France)

The fear of losing my mother, of never seeing her again. (Caregiver from Switzerland)

Fear that cancer might come back. (Person with lung cancer from Spain)

Facing the possibility that I may die soon. Currently accepting that there is no chance for a complete cure. (Person with lung cancer from Hungary)

Fear of dying by suffocation as lung cancer spreads so much that it prevents breathing. (Person with lung cancer from Finland)

Knowing that my mom is on borrowed time. Always wondering how much longer for we have together. And how many more memories can we make before she is too unwell to do anything. (Caregiver from Ireland)

What have been the main emotional challenges you have faced since the lung cancer diagnosis? (open question)*

All participants (n=1,536)

Estimated mentions			
540+	1	**Fear and anxiety**	*"I live with the constant fear that the cancer will come back at any moment."* *"Scan days fill me with unbearable anxiety, fearing bad news."*
380+	2	**Impact on loved ones**	*"I worry deeply about how my children will cope if I'm no longer here."* *"Seeing my family suffer emotionally is harder than the disease itself."*
310+	3	**Depression and hopelessness**	*"There were moments when I no longer wanted to live."* *"I've lost all hope for the future; I feel completely defeated."*
260+	4	**Loneliness and emotional isolation**	*"People disappeared from my life after the diagnosis. I feel abandoned."* *"Even when surrounded by others, I feel completely alone."*
240+	5	**Coping with treatment and side effects**	*"The chemotherapy left me physically and emotionally exhausted."* *"I struggled to accept my appearance after losing my hair and strength."*
180+	6	**Shock, denial, and disbelief**	*"The diagnosis hit me like a punch in the stomach. I couldn't believe it."* *"I kept thinking, this can't be happening to me."*
170+	7	**Loss of control and identity**	*"I no longer recognise myself. I feel like a shadow of who I was."* *"I've lost control over my life, my plans, and my body."*
140+	8	**Practical and work-related difficulties**	*"I had to stop working suddenly, which left me in financial chaos."* *"Not being able to drive anymore made me completely dependent on others."*
120+	9	**Lack of institutional or medical support**	*"My diagnosis was delivered with no empathy, in a hallway."* *"There was no psychological support offered. I had to manage on my own."*
95+	10	**Existential worries and loss of meaning**	*"I constantly wonder what the point of everything is now."* *"I grieve the life I'll never get to live and the things I'll miss."*

Figure 2. *Main emotional challenges since the diagnosis.*

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* The number of mentions in this open-ended question was analysed using ChatGPT (GPT-5 mini, OpenAI, 2025).

Figure 2 shows the main emotional challenges reported by participants in response to an open-ended question. The most frequently mentioned difficulties were related to fear and anxiety, the impact on loved ones, and feelings of depression and hopelessness.

Issues related to the diagnostic process were reported as the most emotionally distressing experiences along the healthcare journey. **Receiving the lung cancer diagnosis was the most frequent stressful event,** according to 63.62% of participants (Figure 3). Previous research showed that the moment of receiving a cancer diagnosis may be even considered potentially traumatising[6]. Additionally, our findings indicate two other aspects that had a great impact on mental health: receiving additional news beyond the diagnosis (e.g., prognosis and stage of cancer) (39.61%) and the diagnosis process itself (32.47%).

Lung cancer diagnosis, symptoms, and side effects were the most frequent causes of emotional distress.

Beyond the diagnostic pathway, **another relevant contributor to emotional distress was the management of physical symptoms and side effects,** reported by 45.52% of participants. These are often poorly managed, causing a significant burden for both

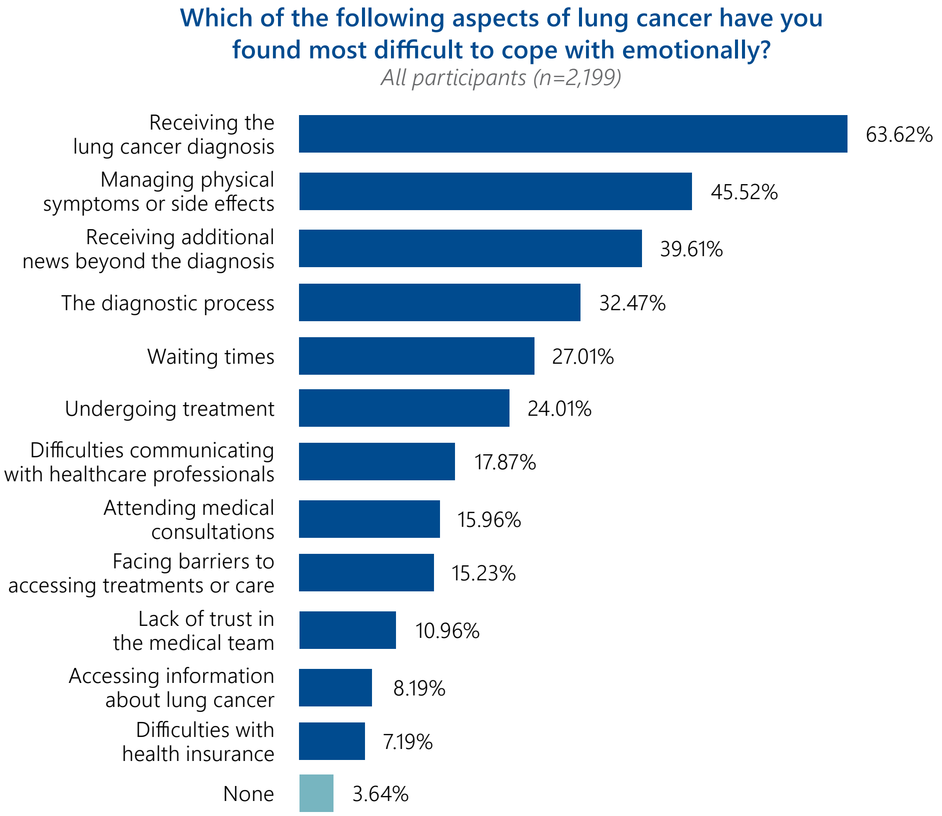

Figure 3. *Healthcare related issues with impact on mental health.*

patients and their loved ones[7]. Literature has identified strong associations between greater emotional problems, lower quality of life, and greater symptom burden[3]. For example, previous research has shown that the presence of pain is strongly associated with depression and anxiety in people with lung cancer[8].

According to our 7th LuCE Report (2022), education about side effects was the top priority for participants before diagnosis and treatment, while support for managing them became the most important need during and after treatment[9]. The main suggestions for improving support included referrals to allied health professionals, education on self-management, and better access to the medical and nursing team.

As illustrated in Table 9, **caregivers tended to experience greater negative mental health impact from healthcare-related challenges** than patients. They reported higher impact from issues such as the diagnostic process (40.08% *vs.* 30.26%), waiting times (34.82% *vs.* 24.75%), difficulties communicating with healthcare professionals (24.29% *vs.* 16.01%), and facing barriers to accessing treatments or care (23.48% *vs.* 12.84%). There is only one item reported more frequently by patients: managing physical symptoms or side effects (46.57% *vs.* 41.90%).

Which of the following healthcare related issues have had the greatest impact on your mental health?
Comparison between patients and caregivers

	People with LC (n=1,705)	Caregivers (n=494)
Receiving the lung cancer diagnosis	62.58%	67.21%
Managing physical symptoms or side effects	46.57%	41.90%
Receiving additional news beyond the diagnosis	38.24%	44.33%
The diagnostic process	30.26%	40.08%
Waiting times	24.75%	34.82%
Undergoing treatment	23.64%	25.30%
Difficulties communicating with healthcare professionals	16.01%	24.29%
Attending medical consultations	14.31%	21.66%
Facing barriers to accessing treatments or care	12.84%	23.48%
Lack of trust in the medical team	9.03%	17.61%
Accessing information about lung cancer	7.92%	9.11%
Difficulties with health insurance	6.57%	9.31%
None	4.34%	1.21%

Table 9. *Healthcare related issues with impact on mental health (patients vs. caregivers).*

That my complaints were dismissed by several doctors as problems with aging or imagination; being too demanding. *(Person with lung cancer from Germany)*

I have often felt like a cancer diagnosis, not like a whole person in the hospital system. *(Person with lung cancer from Denmark)*

Anxiety due to lack of access to tests and medicines. *(Person with lung cancer from Spain)*

Waiting for results from scans was the worst. *(Person with lung cancer from The United Kingdom)*

Sadness due to side effects not understood by some medical staff. *(Person with lung cancer from France)*

The healthcare system where my relative was treated is of an unacceptable standard. *(Caregiver from Hungary)*

Trauma due to error/missed diagnosis. *(Person with lung cancer from The Netherlands)*

I had to lose my job because I had to take my mother for infusions. Why? To stand in queues for paperwork, beds, to be infused, to see doctors. Why? Because the process is unorganized and you spend half a day at the hospital every week. Also tests and diagnostics outside the center had to be done on other days. *(Caregiver from Ukraine)*

As Figure 4 shows, **9 out of 10 participants experienced emotional difficulties affecting their daily lives following a lung cancer diagnosis.** A total of 42.99% reported experiencing these difficulties occasionally and felt they were able to manage them. However, 46.31% indicated they faced emotional challenges frequently or even constantly with a considerable (medium to high) impact on their daily lives.

Consistent with patterns observed throughout the report, **women reported greater daily life disruption due to lung cancer than men,** with a statistically significant difference between genders*. While 63.46% of men indicated that they experienced no or only occasional manageable emotional difficulties, this proportion was lower among women at 51.29%.

Similarly, age appears to influence the frequency and severity of emotional challenges. **Younger participants (aged 18-64) reported more frequent and severe emotional disruptions to daily life** following a lung cancer diagnosis compared with older participants (older than 64)**.

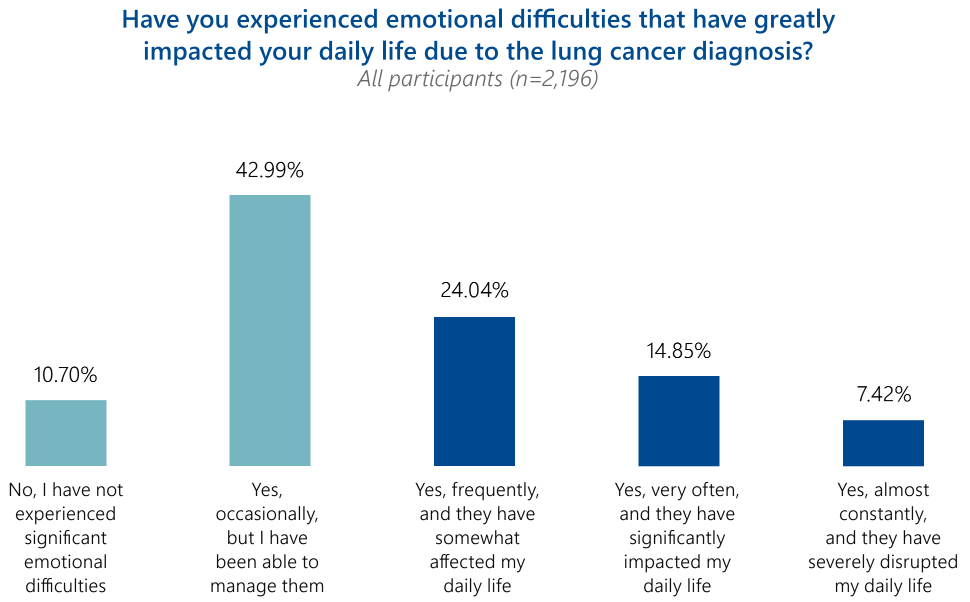

Figure 4. *Prevalence of emotional difficulties with a great impact on daily life.*

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* t(2157) = 5.6575, p < .001. Cohen's d = 0.29.

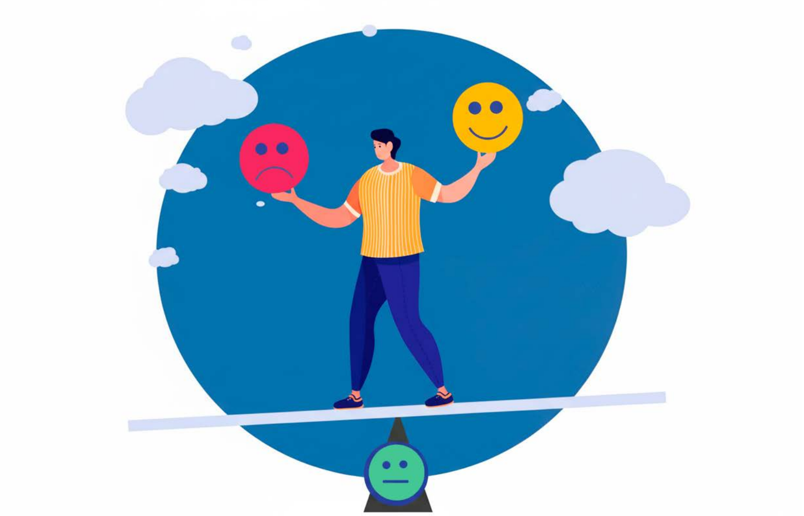
** t(2154) = 10.022, p < .001. Cohen's d = 0.47

Our survey continued to observe that individuals diagnosed with lung cancer reported a lower impact of emotional difficulties on their daily lives and were more likely to manage these difficulties effectively (Table 10). **Caregivers were significantly more likely to report frequent, severe, and constant emotional difficulties** compared to people with lung cancer*. A total of 12.68% of patients did not report significant emotional difficulties, compared to 3.85% of caregivers. Additionally, 46.92% of patients stated that although they experienced emotional difficulties, they felt able to manage them, compared to 29.41% of caregivers.

Have you experienced emotional difficulties that have greatly impacted your daily life due to the lung cancer diagnosis?
Comparison between patients and caregivers

	People with LC (n=1,703)	Caregivers (n=493)
No, I have not experienced significant emotional difficulties	12.68%	3.85%
Yes, occasionally, but I have been able to manage them	46.92%	29.41%
Yes, frequently, and they have somewhat affected my daily life	22.61%	29.01%
Yes, very often, and they have significantly impacted my daily life	12.68%	22.31%
Yes, almost constantly, and they have severely disrupted my daily life	5.11%	15.42%

Table 10. *Prevalence of emotional difficulties with great impact on daily life (patients vs. caregivers)*



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* t(2194) = 12.14, p < .001. Cohen´s d = 0.62.

The data from this research indicate that lung cancer has a significant impact on mental health. When asked how mental health (not the lung cancer itself) had impacted their lives, most participants reported some level of impact (Figure 5).

Half of the participants reported a high impact of mental health on their social life and lifestyle.

- **Social life and lifestyle were cited as the main areas affected by their mental health,** with 48% of participants reporting a high impact (by very much / quite a bit). Only 9.34% of respondents stated that this domain was not affected by their mental health. Social life was significantly more negatively affected in younger participants (aged 18-64), comparted to older participants (older than 64)*.

- **Finances and work-related aspects were also notably affected.** Three out of four survey respondents (77.24%) reported some level of impact, with over 44.91% indicating they were highly affected (by very much / quite a bit). Thus, our research suggests a two way relationship: mental health may negatively affect finances, while our 8th LuCE Report (2023) showed that financial difficulties, in turn, primarily impact on mental health[10].

  Our research again found that **women reported a greater negative impact of their mental health on their finances and work life** compared to men following a lung cancer diagnosis**. Specifically, 46.43% of women reported a high impact, compared to 38.40% of men. On the other hand, a low impact was reported by 37.39% of women and 46.21% of men.

  Our findings show that mental health had a **significantly greater negative impact on work and finances for individuals impacted by advanced lung cancer** (Stage III-IV) compared with those by Stage I–II lung cancer***. In addition, **younger adults (aged 18-64) reported a significantly greater negative impact on work and finances** due to mental health than older adults (older than 64)****.

- In contrast, **family life,** while still affected, showed a **slightly more balanced distribution of responses.** Around 36% reported a high impact (by very much / quite a bit), and 14.63% indicated that their family life was not affected by emotional difficulties (by not at all). Once again, younger respondents (aged 18-64) experienced significantly more negative consequences*****.

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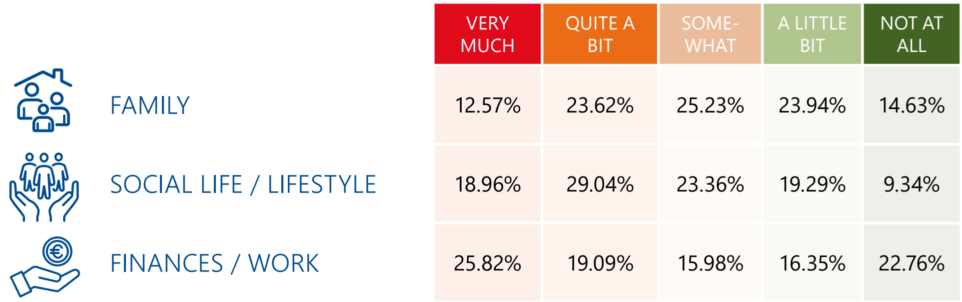
* t(2141) = 7.24, p < .001. Cohen's d = 0.34. ** t(2115) = 3.8999, p < .001. Cohen's d = 0.20.
*** t(2089) = 3.21, p = .001, Cohen's d = 0.16. **** t(2112) = 18.64, p < .001. Cohen's d = 0.89.
***** t(2137) = 7.04, p < .001. Cohen's d = 0.33.

Since the lung cancer diagnosis, to what extent has your mental health (not the lung cancer itself) negatively affected the following areas of your life?

All participants (n=2,199)



	VERY MUCH	QUITE A BIT	SOME-WHAT	A LITTLE BIT	NOT AT ALL
FAMILY	12.57%	23.62%	25.23%	23.94%	14.63%
SOCIAL LIFE / LIFESTYLE	18.96%	29.04%	23.36%	19.29%	9.34%
FINANCES / WORK	25.82%	19.09%	15.98%	16.35%	22.76%

Figure 5. *Extent to which mental health has impacted different areas of life.*

Since the lung cancer diagnosis, to what extent has your mental health (not the lung cancer itself) negatively affected the following areas of your life?

Comparison between patients and caregivers

People with LC (n=1,704)	Very much	Quite a bit	Somewhat	A little bit	Not at all
Family	9.77%	22.08%	26.41%	24.57%	17.17%
Social life / Lifestyle	16.46%	27.73%	24.84%	19.71%	11.27%
Finances / Work	26.25%	18.56%	14.29%	16.10%	24.80%
Caregivers (n=495)	**Very much**	**Quite a bit**	**Somewhat**	**A little bit**	**Not at all**
Family	22.20%	28.92%	21.18%	21.79%	5.91%
Social life / Lifestyle	27.66%	33.61%	18.24%	17.83%	2.66%
Finances / Work	24.39%	20.90%	21.72%	17.21%	15.78%

Table 11. *Extent to which mental health has impacted different areas of life (patients vs. caregivers).*

According to our 6th LuCE Report (2021), a total of 91.2% of individuals impacted by lung cancer 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%)[11].

In this context, it is important to explore how capable patients and caregivers felt in coping with these repercussions within this survey. Our current research findings show that **only 54.81% of participants reported feeling emotionally capable of dealing with all the issues in their lives** (by very much / quite a bit) (Figure 6). Therefore, a significant proportion of respondents (45.19%) experienced some degree of emotional struggle, highlighting the need for greater psychological support and targeted interventions.

Since the diagnosis, have you felt emotionally capable of dealing with all the issues in your life?
All participants (n=2,193)

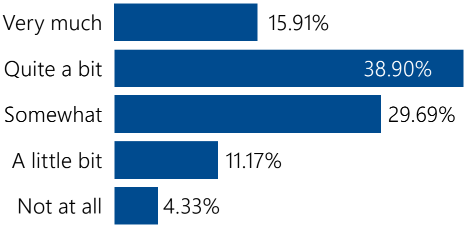


Figure 6. *Perceived emotional capacity to cope with life issues since the diagnosis.*

> *Only 54.81% of participants felt emotionally capable of managing all aspects of their lives*

People diagnosed with lung cancer report feeling significantly more emotionally capable of dealing with life's issues since diagnosis compared to caregivers*. It is concerning that 60.89% of caregivers reported only feeling \`somewhat´, \`a little´, or ´not at all´ capable, compared with 40.66% of patients (Table 12).

Since the diagnosis, have you felt emotionally capable of dealing with all the issues in your life?
Comparison between patients and caregivers

	People with LC (n=1,702)	Caregivers (n=491)
Not at all	3.53%	7.13%
A little bit	9.69%	16.29%
Somewhat	27.44%	37.47%
Quite a bit	40.89%	31.98%
Very much	18.45%	7.13%

Table 12. *Perceived emotional capacity to cope with life issues since the diagnosis (patients vs. caregivers)*

One of the hypotheses is that this difference may be related to the considerable duties and responsibilities assumed by caregivers, such as assisting with activities of living, coordinating care, monitoring treatment, and the provision of emotional and social support[12], which can increase stress and reduce their perceived emotional capacity. The 6th LuCE Report (2021) found that only 32.5% of caregivers felt supported in their role as caregiver, with psychological counselling identified as the most frequently needed form of support (51.9%)[11].

It is also notable that **younger patients (64 or younger) reported feeling less emotionally capable** of managing all the issues in their lives compared to older patients (over 64)**.

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* t(8.7822). p < 0.001. Cohen's d = 0.44.
** t(2151) = 7.87, p < .001. Cohen's d = 0.37.

3.2. WHEN THE MIND STRUGGLES: UNDERSTANDING MENTAL HEALTH DISORDERS IN LUNG CANCER

Prolonged emotional distress, if not addressed, can escalate over time and contribute to the development of clinical depression in some individuals. This is a mental health condition characterized by a low mood or loss of pleasure or interest in activities for long periods of time[13].

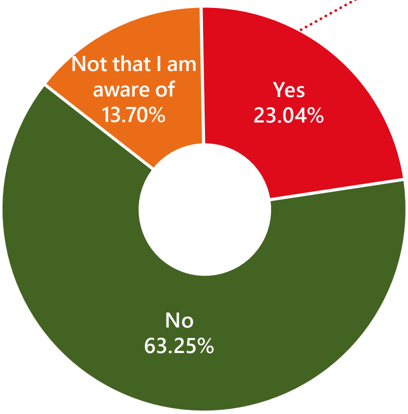
1 in 4 reported having been diagnosed with depression.

Depression is the most common psychiatric disorder in individuals with cancer[14] and the prevalence of major depression highest in those with lung cancer[15]. Depression is associated with reduced quality of life, decreased adherence to treatment, greater mortality, increased healthcare costs and worse satisfaction with care[16-17].

About **1 in 4 (23.04%) of our respondents reporting having ever been diagnosed with depression** (Figure 7). Results presented in Table 13 illustrate that this percentage was slightly higher in patients (23.96%) compared to caregivers (19.51%). It is important to highlight that **most participants with depression or a history of depression (76.61%) reported being diagnosed prior to the lung cancer,** while only 23.31% were diagnosed after.

Have you ever been diagnosed with depression?

All participants (n=1,992)



76.69% - Diagnosis of depression before lung cancer

23.31% - Diagnosis of depression after lung cancer

Figure 7. *Prevalence of diagnosed depression.*

Have you ever been diagnosed with depression? *Comparison between patients and caregivers*

	People with LC (n=1,582)	Caregivers (n=410)
Yes	23.96%	19.51%
No	62.58%	65.85%
Not that I am aware of	13.46%	14.63%

Table 13. *Prevalence of diagnosed depression (patients vs. caregivers)*

Among those diagnosed with depression before a lung cancer diagnosis (Figure 8), 44.23% reported that they did not experience depression afterward. However, **21.41% experienced a relapse after the lung cancer diagnosis, and for 15.49%, their depression worsened.**

QUESTION ASKED OF PARTICIPANTS DIAGNOSED WITH DEPRESSION BEFORE A LUNG CANCER DIAGNOSIS (n=355)

Did you experience a relapse of depression or did it worsen after the lung cancer diagnosis?

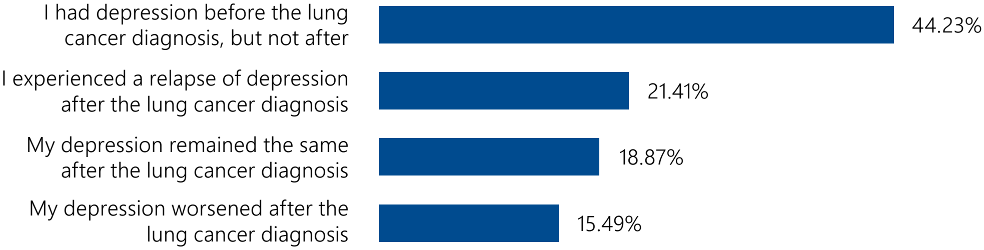


Figure 8. *Depression worsening or relapse after lung cancer diagnosis.*

Our survey findings suggest that depression is more strongly associated with the experience of lung cancer in caregivers than in patients; particularly among those with a prior history of depression. **Caregivers were significantly more likely than patients to experience a relapse of depression following a lung cancer diagnosis** (35.29% *vs.* 19.08%)*.

Additionally, as shown in Table 14, 46.71% of patients reported having experienced depression before the lung cancer diagnosis but not afterward. This percentage was notably lower among caregivers (29.41%), further highlighting the emotional vulnerability of caregivers in the context of lung cancer.

Did you experience a relapse of depression, or did it worsen after the lung cancer diagnosis? *Comparison between patients and caregivers*

	People with LC (n=304)	Caregivers (n=51)
I had depression before the lung cancer diagnosis, but not after	46.71%	29.41%
I experienced a relapse of depression after the lung cancer diagnosis	19.08%	35.29%
My depression remained the same after the lung cancer diagnosis	18.09%	23.53%
My depression worsened after the lung cancer diagnosis	16.12%	11.76%

Table 14. *Depression worsening or relapse after lung cancer diagnosis (patients vs. caregivers)*

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* t(353) = -3.051, p = 0.002, Cohen's d = -0.46

QUESTION ASKED OF PARTICIPANTS DIAGNOSED WITH DEPRESSION AFTER A LUNG CANCER DIAGNOSIS OR CONTINUED TO EXPERIENCE THIS MENTAL HEALTH DISORDER AFTERWARDS *(n=299)*

What types of support have you received for your depression?

Medication	**66.22%**
Psychological therapy / counselling	**53.85%**
Support groups / patient organisations	**14.38%**
Digital resources (e.g., apps, websites, etc.)	**10.70%**
No support received	**14.72%**

Table 15. *Types of support received for depression.*

What types of support have you received for your depression?

Comparison between patients and caregivers

	People with LC (n=235)	Caregivers (n=64)
Medication	66.38%	65.63%
Psychological therapy / counselling	51.91%	60.94%
Support groups / patient organisations	13.62%	17.19%
Digital resources (apps, websites, etc.)	9.36%	15.63%
No support received	14.89%	14.06%

Table 16. *Types of support received for depression (patients vs. caregivers).*

Although depression is an important complication of lung cancer, there are still significant barriers on access to adequate treatment and support.

According to the literature, most individuals with cancer diagnosed with depression did not receive treatment for their depression[15].

The following two questions were asked only to participants who had been diagnosed with depression after lung cancer diagnosis or continued to experience this mental health disorder afterwards.

As illustrated in Table 15, **only 66.22% of individuals impacted by lung cancer and diagnosed with depression received medication and 53.85% accessed psychological therapy or counselling.**

According to the literature, antidepressants should be restricted to people with cancer experiencing moderate-to-severe depressive symptoms considering their overall health status[18]. Psychosocial interventions should be the first-line approach for individuals with mild depression, with medication considered only if these interventions do not achieve the desired outcomes.

The **data reported by patients is especially concerning,** as caregivers appear to have accessed psychological therapy (60.94% *vs.* 51.91%), peer support (17.19% *vs.* 13.62%), and digital resources (15.63 *vs.* 9.36%) more frequently than patients (Table 16).

Medication was the most reported form of support for both groups, with very similar usage rates (66.38% for patients and 65.63% for caregivers).

QUESTION ASKED OF PARTICIPANTS DIAGNOSED WITH DEPRESSION AFTER A LUNG CANCER DIAGNOSIS OR CONTINUED TO EXPERIENCE THIS MENTAL HEALTH DISORDER AFTERWARDS (n=290)

How would you rate the treatment or support you received for your depression?

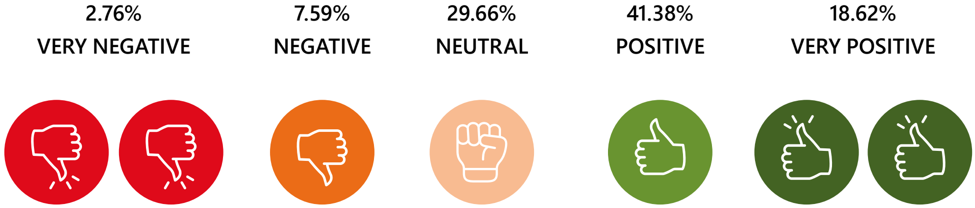

Figure 10. *Perceived quality of treatment or support received for depression.*

6 in 10 individuals with depression after a lung cancer diagnosis reported being satisfied with the treatment they received.

Only 60% of participants who experienced depression after a lung cancer diagnosis positively valued the treatment and support they received for depression (Figure 10). This suggests that a significant proportion of people impacted by lung cancer and depression may not have received the level of care they needed.

Our survey does not reveal differences between the responses collected from people with lung cancer and caregivers (Table 17).

Improving support for people with depression is fundamental to reducing the psychological burden of managing both conditions simultaneously. Evidence from the literature also shows that individuals with depression or anxiety are more likely to engage in unhealthy habits[19], and have low adherence to medical appointments and treatments[20]. Addressing mental health more effectively could therefore not only improve emotional well-being but also support better clinical outcomes in lung cancer care.

How would you rate the treatment or support you received for your depression? *Comparison between patients and caregivers*

	People with LC (n=227)	Caregivers (n=63)
Very positive	18.50%	19.05%
Positive	41.41%	41.27%
Neutral	29.52%	30.16%
Negative	7.93%	6.35%
Very negative	2.64%	3.17%

Table 17. *Perceived quality of treatment or support received for depression (patients vs. caregivers)*

As previously noted, 23.04% of participants reported depression diagnosis, while 76.96% indicated they had not*. However, **among those without a diagnosis** (n=1,528), **only 63.55% were sure that they had not experienced depression** after a lung cancer diagnosis (Figure 11). Worryingly, 15.18% believed they had experienced depression, and 21.27% were unsure**.

It is worth noting that only 65.89% of patients and 55.02% of caregivers were sure that they did not have depression after the lung cancer diagnosis (Table 18).

These findings reinforce what previous research has shown: **depression is likely undertreated among people affected by lung cancer[15].** While our results do not suggest that any participants were underdiagnosed with depression, it is important to note that some participants perceived themselves as having depression. However, this perception does not necessarily correspond to a clinical diagnosis. This highlights the importance of monitoring individuals in more emotionally vulnerable situations who may be at higher risk.

QUESTION ASKED OF PARTICIPANTS WITHOUT A DIAGNOSIS OF DEPRESSION *(n=1,528)*

Do you think that you have (or have had) depression after the lung cancer diagnosis?

YES	15.18%
NOT SURE	21.27%
NO	63.55%

Figure 11. *Perceived depression following lung cancer diagnosis.*

Do you think that you have (or have had) depression after the lung cancer diagnosis?
Comparison between patients and caregivers

	People with LC (n=1,199)	Caregivers (n=329)
Yes	14.18%	18.84%
No	65.89%	55.02%
I am not sure	19.93%	26.14%

Table 18. *Perceived depression following lung cancer diagnosis (patients vs. caregivers)*

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* `No´ (63.25%); `Not that I am aware of´ (13.70%)

** To clarify the question and avoid the confusion between depression and sadness, the survey included the following explanatory note: `Depression is a mental health condition characterized by a low mood or loss of pleasure or interest in activities for long periods of time. This is different from regular mood changes and feelings about everyday life. Depressive episodes last most of the day, nearly every day, for at least two weeks´

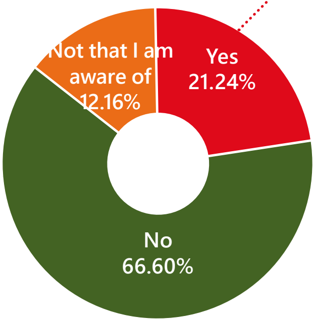
Anxiety is another mental health disorder with higher prevalence in people impacted by lung cancer compared with the general population[21]. An anxiety disorder is more serious than occasionally feeling anxious. It is a mental health condition characterized by a persistent anxiety that does not go away and can worsen over time[22]. The highest levels of anxiety are reported in lung, gynaecological, and haematological cancers[23]. The symptoms can interfere with daily activities such as job performance, schoolwork, and relationships. Additionally, it can worsen existing medical symptoms and can interfere with cancer care[24].

1 in 5 was diagnosed with an anxiety disorder, more commonly in women and often before the lung cancer diagnosis.

Our research shows that **1 in 5 participants (21.24%) had received a diagnosis of anxiety,** with most of these cases (70.55%) occurring prior to their lung cancer diagnosis (Figure 12).

There were not relevant differences in responses from patients and caregivers (Table 19). However, the results revealed a statistically significant difference between women and men[*]. **Women were more likely than men to have been diagnosed with an anxiety disorder** (23.47% *vs.* 13.32%). Additionally, there was a statistically significant difference in the prevalence of anxiety disorder diagnoses between respondents with early- and advanced-stage lung cancer, as well as between younger (aged 18-64) and older participants (aged over 64). Our research suggests that individuals impacted by **advanced-stage cancer (Stage III-IV)**[**] **and younger participants (aged 18-64)**[***] **were more likely to have been diagnosed with an anxiety disorder** (either before or after diagnosis).

Have you ever been diagnosed with an anxiety disorder?
All participants (n=1,982)



70.55% - Diagnosis of anxiety before lung cancer

29.45% - Diagnosis of anxiety after lung cancer

Figure 7. *Prevalence of diagnosed depression.*

Have you ever been diagnosed with an anxiety disorder? *Comparison between patients and caregivers*

	People with LC (n=1,575)	Caregivers (n=407)
Yes	21.59%	19.90%
No	67.11%	64.62%
Not that I am aware of	11.30%	15.48%

Table 19. *Prevalence of diagnosed anxiety disorder (patients vs. caregivers)*

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[*] t(1949) = –3.1823, p = 0.001. Cohen's d = –0.17. [**] t(1929) = 3.36, p < .001. Cohen's d = 0.17.
[***] t(1947) = -3.194, p = 0.001. Cohen's d = -0.16.

For participants with a prior anxiety disorder, the lung cancer diagnosis had a significant impact on their mental health. As a result, half (52.53%) experienced a relapse or worsening of their anxiety following the lung cancer diagnosis (Figure 13).

It is worth noting that 19.19% of individuals with pre-existing anxiety did not experience it after the lung cancer diagnosis. By contrast, as shown previously in Figure 8, 44.23% of people diagnosed with depression before lung cancer reported no longer having it afterward. These findings suggest that individuals with a history of anxiety are more likely to relapse after a lung cancer diagnosis than those with a history of depression.

QUESTION ASKED OF PARTICIPANTS DIAGNOSED WITH ANXIETY BEFORE A LUNG CANCER DIAGNOSIS *(n=297)*

Did you experience a relapse of the anxiety disorder or did it worsen after the lung cancer diagnosis?

Figure 13. *Anxiety disorder worsening or relapse after lung cancer diagnosis.*

Further analysis of our research shows a statistically significant difference between patients and caregivers. **Caregivers were more likely than patients to experience a relapse or worsening of an existing anxiety disorder after the lung cancer diagnosis[*].** In total, 37.04% of caregivers experienced a relapse, compared with 20.58% of patients (Table 20).

Did you experience a relapse of the anxiety disorder, or did it worsen after the lung cancer diagnosis? *Comparison between patients and caregivers*

	People with LC (n=243)	Caregivers (n=54)
My anxiety worsened after the lung cancer diagnosis	28.81%	29.63%
My anxiety remained the same after the lung cancer diagnosis	27.57%	31.48%
I experienced a relapse of the anxiety disorder after the lung cancer diagnosis	20.58%	37.04%
I had anxiety before the lung cancer diagnosis, but not after	23.05%	1.85%

Table 20. *Anxiety disorder worsening or relapse after lung cancer diagnosis (patients vs. caregivers)*

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[*] t (295) = -3.749, p < .001, Cohen's d = -0.56.

QUESTION ASKED OF PARTICIPANTS DIAGNOSED WITH ANXIETY AFTER A LUNG CANCER DIAGNOSIS OR CONTINUED TO EXPERIENCE THIS MENTAL HEALTH DISORDER AFTERWARDS *(n=361)*

What types of support have you received for your anxiety disorder?

Medication	**60.39%**
Psychological therapy / counselling	**54.02%**
Support groups / patient organisations	**12.47%**
Digital resources (e.g., apps, websites, etc.)	**10.25%**
No support received	**13.85%**

Table 21. *Types of support received for anxiety.*

What types of support have you received for your anxiety disorder?

Comparison between patients and caregivers

	People with LC (n=282)	Caregivers (n=79)
Medication	62.77%	51.90%
Psychological therapy / counselling	53.19%	56.96%
Support groups / patient organisations	11.35%	16.46%
Digital resources (apps, websites, etc.)	10.28%	10.13%
No support received	12.77%	17.72%

Table 22. *Types of support received for anxiety (patients vs. caregivers)*

The following two questions were asked only to participants who had been diagnosed with an anxiety disorder after the lung cancer diagnosis or continued to experience this mental health disorder afterwards.

The treatment support rates for anxiety disorders are similar to those for depression. Thus, this research also highlights barriers to accessing treatment for people impacted by lung cancer and diagnosed with anxiety disorder.

Table 21 indicates that the combination of medication and psychological therapy was not provided in a large proportion of cases. **Only 60.39% had received medication and 54.02% psychotherapy or counselling.**

Digital resources have emerged in recent years as valuable tools for reducing symptoms of anxiety when used alone, or as an adjunct to anti-anxiety medications[25]. Similarly, peer support interventions (online or in-person) appear to be feasible and acceptable, with a strong potential for people with mental health conditions[26-27].

However, our findings show a low take up of these services: only a minority of people with lung cancer or caregivers engage with support groups or received assistance from patient organisations (12.47%), and even fewer used digital resources (10.25%) to help manage their anxiety disorder.

Table 22 shows that **patients more frequently reported receiving medication for anxiety** (62.77% *vs.* 51.90%), whereas caregivers more often engaged with support groups or patient organisations (16.46% *vs.* 11.35%).

QUESTION ASKED OF PARTICIPANTS DIAGNOSED WITH ANXIETY AFTER LUNG CANCER DIAGNOSIS OR CONTINUED TO EXPERIENCE THIS MENTAL HEALTH DISORDER AFTERWARDS *(n=352)*

How would you rate the treatment or support you received for your anxiety disorder?

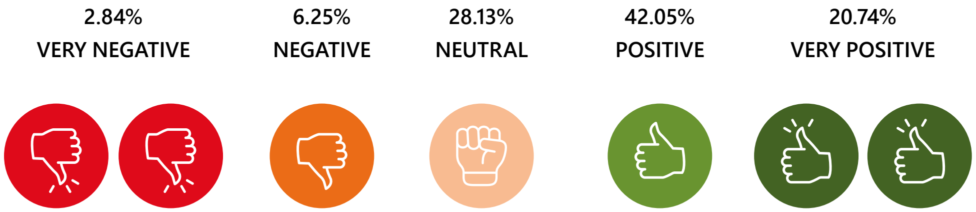

Figure 14. *Perceived quality of treatment or support received for anxiety.*

Among respondents who had experienced an anxiety disorder after a lung cancer diagnosis, only 62.79% rated the treatment or support they received positively (Figure 14). Nearly 1 in 10 gave a negative rating. The high proportion of neutral responses (approximately 1 in 4) highlights a need to improve the quality and impact of mental health support.

Table 23 shows that positive ratings were more common among caregivers (67.09%) than among patients (61.54%). Additionally, **patients were twice as likely as caregivers to report a negative experience** (10.26% *vs.* 5.06%). These findings suggest the presence of barriers to effective or accessible mental health care, especially for people living with lung cancer, particularly patients.

How would you rate the treatment or support you received for your anxiety disorder? *Comparison between patients and caregivers*

	People with LC (n=273)	Caregivers (n=79)
Very positive	19.05%	26.58%
Positive	42.49%	40.51%
Neutral	28.21%	27.85%
Negative	7.33%	2.53%
Very negative	2.93%	2.53%

Table 23. *Perceived quality of treatment or support received for anxiety (patients vs. caregivers)*

15% of participants without a diagnosis of anxiety believed they had an anxiety disorder.

As cited earlier, 21.24% of participants reported having received an anxiety disorder diagnosis, while 78.76% indicated they had not[*]. However, among those without a diagnosis (n=1,556), **only 66.58% were confident that they had not experienced anxiety** after a lung cancer diagnosis. Worryingly, 15.55% believed they had experienced anxiety, and 17.87% were unsure[**] (Figure 15).

Caregivers perceived a higher level of anxiety. While 69.37% of patients were confident that they had not experienced an anxiety disorder, this dropped to 56.00% among caregivers (Table 24).

QUESTION ASKED OF PARTICIPANTS WITHOUT A DIAGNOSIS OF DEPRESSION

(n=1,556)

Do you think that you have (or have had) anxiety disorder after the lung cancer diagnosis?

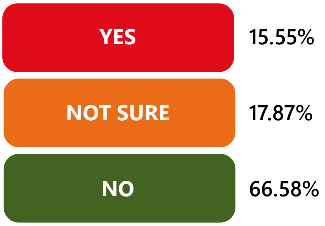

Figure 15. *Perceived anxiety disorder following lung cancer diagnosis.*

Do you think that you have (or have had) anxiety disorder after the lung cancer diagnosis?
Comparison between patients and caregivers

	People with LC (n=1,231)	Caregivers (n=325)
Yes	14.62%	19.08%
No	69.37%	56.00%
Not that I am aware of	16.00%	24.92%

Table 24. *Perceived anxiety disorder following lung cancer diagnosis (patients vs. caregivers)*

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[*] No (63.25%); Not that I am aware of (13.70%).

[**] To clarify the question and avoid the confusion between anxiety disorder and ordinary feelings of anxiety, the survey included the following explanatory note: `Everyone can feel anxious sometimes, but people with anxiety disorders often experience fear and worry that is both intense and excessive. These feelings are difficult to control, cause significant distress and can last a long time if untreated´.

Psychiatric or mental health disorders are often both underdiagnosed and under-treated, affecting the quality of life of those affected[18]. In this context, it is important to explore individuals' experiences to identify those who may be at risk of depression or anxiety. As shown in Figure 16, **most participants reported symptoms associated with depression or anxiety** during the two weeks prior to completing the survey.

While the frequency of symptoms is key to identifying a potential depressive or anxiety disorder—and there may be overlap between symptoms of depression and those caused by the disease or treatment[18]—our findings indicate that a significant proportion of participants were experiencing psychological vulnerability at the time of the survey.

More concerning is that around **20-30% of participants reported experiencing these symptoms frequently** (`nearly every day´ or `more than half the days´). **The most frequently reported issues were feeling nervous or anxious and difficulty sleeping.** Around 32% of participants frequently felt nervous, anxious, or on edge, and a similar proportion experienced sleeping difficulties. These findings align with the 6th LuCE Report (2021), which identified sleep disturbances as the third most impactful factor on patients' quality of life - after fatigue and weight changes - and the most impactful for caregivers[11].

Around 1 in 4 participants reported symptoms of depression or anxiety.

These findings represent a significant burden on both patients and caregivers, thus impacting overall quality of life.

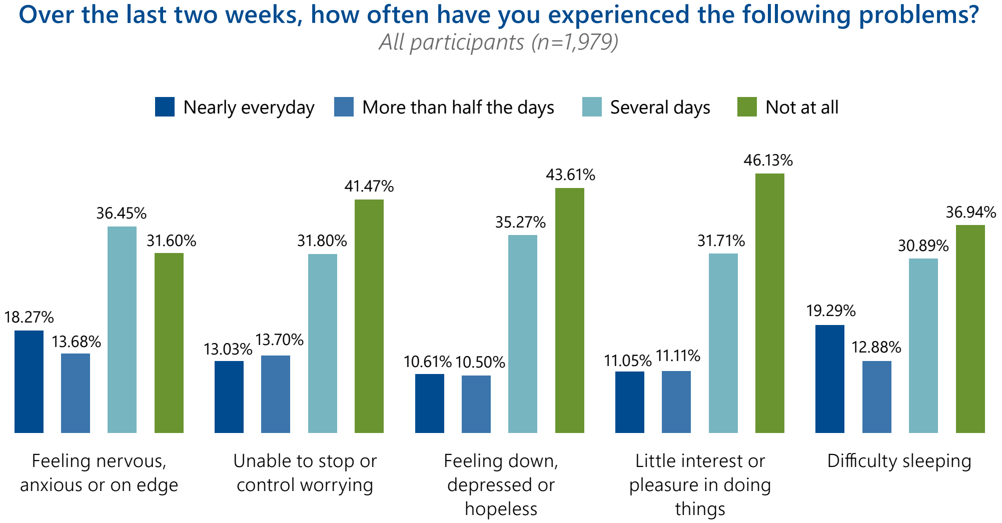
Over the last two weeks, how often have you experienced the following problems?
All participants (n=1,979)

Figure 16. *Frequency of depression and anxiety symptoms experienced in the past two weeks.*

Caregivers reported significantly higher levels of emotional distress across all five indicators compared to people with lung cancer[*] (Table 25). A total of 48.63% of caregivers stated that they felt nervous or anxious frequently, compared to 27.67% of patients. Similarly, 42.78% of caregivers reported being unable to stop or control worrying, while this proportion was 22.62% among patients.

Across all five items, women and younger participants (aged 18-64) reported significantly higher symptom levels over the past two weeks. The most pronounced differences between genders were observed in the first three items: feeling nervous, anxious, or on edge[*]; unable to stop or control worrying[**]; and feeling down, depressed, or hopeless[***].

A similar pattern emerged with age. **Younger participants (aged 18-64) reported more frequent symptoms of anxiety, depression, and poor sleep quality** compared to older participants (aged over 64). Across all emotional and psychological indicators, younger individuals consistently reported significantly higher levels of distress, with the largest difference observed in feelings of nervousness, anxiety, or being on edge[****].

Over the last two weeks, how often have you experienced the following problems?
Comparison between patients and caregivers

People with LC (n=1,575)				
	Nearly everyday	More than half the days	Several days	Not at all
Feeling nervous, anxious or on edge	14.70%	12.97%	37.55%	34.79%
Unable to stop or control worrying	10.14%	12.48%	31.84%	45.55%
Feeling down, depressed or hopeless	7.72%	9.40%	35.02%	47.86%
Little interest or pleasure in doing things	8.89%	9.74%	31.96%	49.41%
Difficulty sleeping	17.98%	12.56%	30.61%	38.85%
Caregivers (n=404)				
	Nearly everyday	More than half the days	Several days	Not at all
Feeling nervous, anxious or on edge	32.17%	16.46%	32.17%	19.20%
Unable to stop or control worrying	24.30%	18.48%	31.65%	25.57%
Feeling down, depressed or hopeless	21.75%	14.75%	36.25%	27.25%
Little interest or pleasure in doing things	19.40%	16.37%	30.73%	33.50%
Difficulty sleeping	24.43%	14.11%	31.99%	29.47%

Table 25. *Frequency of depression and anxiety symptoms experienced in the past two weeks (patients vs. caregivers).*

---

[*] t(1957) = 9.19, p < .001, Cohen's d = 0.51. [*] t (1929) = 5.7083, p < .001. Cohen's d = 0.31.
[**] t (1904) = 5.4997, p < .001. Cohen's d = 0.30. [***] t (1912) = 4.6326, p < .001. Cohen's d = 0.25.
[****] t(1927) = 8.9700, p < .001. Cohen's d = 0.44.

Research has shown that a cancer diagnosis increases the risk of suicide by approximately 1.5 times compared to the general population[28]. This risk varies by cancer type, with people diagnosed with lung cancer –particularly elderly, widowed, male patients and those with unfavourable tumour characteristics– at highest risk[29]. The risk is significantly higher within the first year post diagnosis than in subsequent years[30].

> *Because of the possibility that he might do something to himself; we never told him his life was ending.* *(Caregiver from Slovenia)*

According to our survey, **8.07% of participants reported suicidal thoughts,** and 2.22% had thoughts of self-harm (Figure 17). The results are particularly concerning given that **43.97% reported having felt extremely sad, 24.68% felt trapped, and 21.16% experienced persistent feelings of hopelessness or worthlessness** since diagnosis. In total, 60.48% of participants stated that they had experienced at least one of the listed response options.

44% reported feeling extremely sad, and 24% felt trapped.

These findings reveal a high number of participants in a state of emotional vulnerability, with some potentially meeting the criteria for a diagnosis of depression. Identifying high-risk individuals is crucial for ensuring closer monitoring of mental health disorders, including suicide risk, as well as providing psychological and psychiatric assessment, support, and counselling[30].

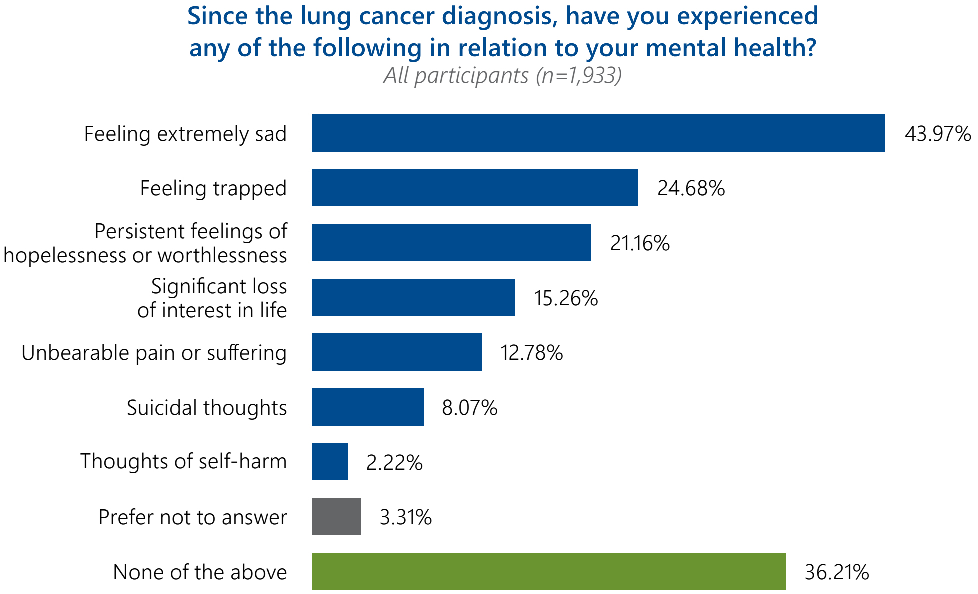

Figure 17. *Prevalence of suicidal risk symptoms since the diagnosis.*

Table 26 shows that **caregivers reported greater emotional distress** than patients, especially regarding feelings of extreme sadness (56.64% *vs.* 40.68%), unbearable pain or suffering (22.56% *vs.* 10.23%), and persistent feelings of hopelessness or worthlessness (28.32% *vs.* 19.30%).

The only exception was suicidal thoughts, which were reported slightly more common among patients than caregivers (8.21% *vs.* 7.52%).

Since the lung cancer diagnosis, have you experienced any of the following in relation to your mental health?
Comparison between patients and caregivers

	People with LC (n=1,534)	Caregivers (n=399)
Feeling extremely sad	40.68%	56.64%
Feeling trapped	23.27%	30.08%
Persistent feelings of hopelessness or worthlessness	19.30%	28.32%
Significant loss of interest in life	14.28%	19.05%
Unbearable pain or suffering	10.23%	22.56%
Suicidal thoughts	8.21%	7.52%
Thoughts of self-harm	1.83%	3.76%
Prefer not to answer	3.06%	4.26%
None of the above	39.57%	23.31%

Table 26. *Prevalence of suicidal risk symptoms since the diagnosis (patients vs. caregivers)*

3.3. THE POWER OF SELF-CARE AND SUPPORT: EXPERIENCES AND NEEDS ALONG THE LUNG CANCER JOURNEY

Maintaining a healthy lifestyle was reported as the main coping strategy.

This report highlights that lung cancer is a major challenge for the mental health of those affected. Supporting psychological well-being is essential for coping with the disease, and there are various strategies that may help individuals live with lung cancer in the best possible way.

Half of the participants agreed that **maintaining a healthy lifestyle** helped them to maintain good mental health (Figure 18). Factors such as exercise, nutrition and rest may have a major impact on both patients and caregivers, either positively or negatively. For example, depression and anxiety disorders have been linked to sedentary behaviour, and poor sleep quality[31]. Our survey shows the importance of a healthy lifestyle is, particularly for mental well-being. Strikingly, our 6th LuCE Report (2022) found these areas rank among the main informational needs identified by people impacted by lung cancer[11].

Participants also identified several key sources of support, including **seeking help from loved ones** (45.47%), **dedicating time to leisure and hobbies** (36.02%), and **receiving support from peers** (34.96%).

Table 27 shows that individuals with lung cancer reported the use more coping strategies to maintain their mental health compared to caregivers. Patients more frequently cited maintaining a healthy lifestyle (53.19% *vs.* 34.89%), dedicating time for leisure (38.39% *vs.* 26.78%), and peer support (37.51% *vs.* 25.06%), while caregivers were more likely to highlight being actively involved in the treatment and care process (39.31% *vs.* 27.83%).

What has helped you to maintain good mental health after the diagnosis of lung cancer?

All participants (n=1,988)

Figure 18. *Factors contributing to maintaining good mental health after the diagnosis.*

What has helped you to maintain good mental health after the diagnosis of lung cancer?

Comparison between patients and caregivers

	People with LC (n=1,581)	Caregivers (n=407)
Maintaining a healthy lifestyle: exercise, diet, etc.	53.19%	34.89%
Seeking support from friends or family	45.10%	46.93%
Dedicating time for leisure and hobbies	38.39%	26.78%
Peer support (other people living with a similar situation)	37.51%	25.06%
Being more involved in the treatment and care	27.83%	39.31%
Engaging in therapy or counselling	22.96%	21.87%
Adopting attitudes of self-compassion and acceptance	23.78%	15.23%
Work / Volunteering	19.23%	20.88%
Meditation, yoga, mindfulness, etc.	18.79%	9.58%
Religion / Spirituality	15.05%	21.62%
Changing something that was harming to my wellbeing	14.48%	7.62%

Table 27. *Factors contributing to maintaining good mental health after the diagnosis (patients vs. caregivers)*

> *It helps me keep my body healthy through physical activities I've always practiced, such as walking, running, and cycling.*
> *(Person with lung cancer from Belgium)*
>
> *Learning to breathe properly with only half a lung.*
> *(Person with lung cancer from Denmark)*
>
> *As a caregiver, receiving information and psychological support to be effective in caring for the person who was ill.*
> *(Caregiver from Greece)*
>
> *My goal from the beginning has been to live, to take care of myself to minimize everything negative about this new phase of my life.*
> *(Person with lung cancer from Spain)*
>
> *Support from ALK+ Facebook group.*
> *(Caregiver from The United Kingdom)*
>
> *Enjoying life in the sense that I have rediscovered its beauty and preciousness: the chance to see, hear, feel, love, and be so grateful to do so.*
> *(Person with lung cancer from France)*
>
> *Not being defined by the diagnosis, treatment, or its aftermath, but continuing to live and make a difference.*
> *(Person with lung cancer from The United Kingdom)*
>
> *No longer letting others decide; firmly expressing my opinion.*
> *(Person with lung cancer from Belgium)*
>
> *When my mother was diagnosed with cancer, the first 6 months were very hard. Intensive socializing with friends and family helped me cope.*
> *(Caregiver from Croatia)*

Lung cancer impacts daily life, routines and family dynamics, as well as the social environment around patients and caregivers[32]. Therefore, preserving a sense of normality becomes a priority for people impacted by lung cancer. Our survey highlights that **living normally and maintaining a sense of normality were the most frequently reported factor influencing mental health** (Figure 19). Although the demands of the disease and its treatment can be an obstacle to maintaining normality, more than half of the participants (53.29%) agreed that this was essential to improving their emotional well-being.

Other response options received a similar percentage of responses, with **`Keeping hope´ as the second most common** (36.54%). Maintaining optimism was identified as a key component in sustaining mental well-being, according to 1 in 3 participants.

The support of loved ones, availability to treatment and care options, and confidence in the medical team were reported as key factors in maintaining mental health. These findings highlight the **central role that both informal and medical support play** in helping individuals cope with the emotional burden of lung cancer.

Medical support, as well as support provided by loved ones, were cited as significant factors influencing mental health.

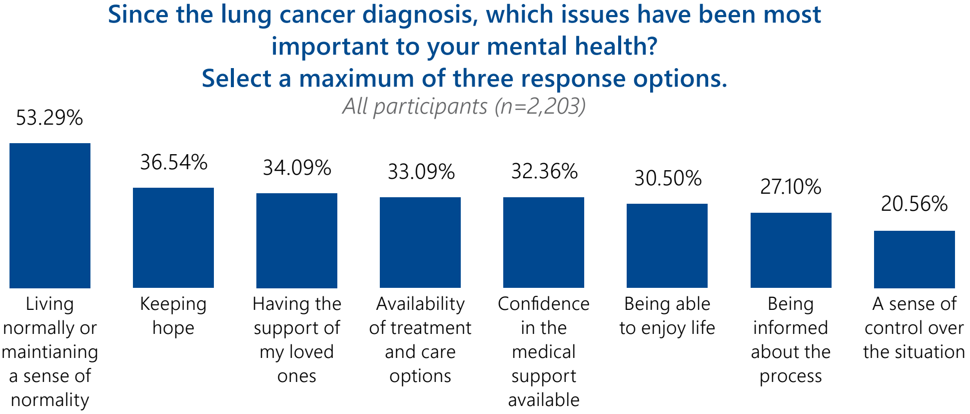

Figure 19. *Key issues supporting mental health since the diagnosis.*

The data illustrated in Table 28 reveal that those diagnosed with lung cancer prioritised maintaining normality, receiving emotional support from loved ones, and enjoying life, whereas caregivers placed greater emphasis on hope, availability to care, and staying informed.

Since the lung cancer diagnosis, which issues have been most important to your mental health? Select a maximum of three response options. *Comparison between patients and caregivers*

	People with LC (n=1,708)	Caregivers (n=495)
Living normally or maintaining a sense of normality	56.79%	41.21%
Keeping hope	34.02%	45.25%
Having the support of my loved ones	37.24%	23.23%
Availability of treatment and care options	29.68%	44.85%
Confidence in the medical support available	32.26%	32.73%
Being able to enjoy life	34.54%	16.57%
Being informed about the process	25.35%	33.13%
A sense of control over the situation	19.09%	25.66%

Table 28. *Key issues supporting mental health since the diagnosis (patients vs. caregivers)*

> *Trusting that care professionals are doing their best for me, and I'm not just a number*
> *(Person with lung cancer from the United Kingdom)*
>
> *Being able to continue doing many things as usual.*
> *(Person with lung cancer from The Netherlands)*
>
> *Continuing to live as normally as possible without thinking about the illness.*
> *(Person with lung cancer from Croatia)*

Even when most participants (71.33%) had not undertaken any of the options in Figure 20, which may have been to reduce their emotional distress, it is notable that 1 in 10 reported delegating decision-making to the healthcare team for this reason. It is also remarkable that 8.90% recognised that they had hidden information from their loved ones.

> *I specifically asked not to be given prognoses... clinical nature of my lung consultant's letters were a disappointment...*
> *(Person with lung cancer from The United Kingdom)*

Table 29 shows that there were no differences in responses between people with lung cancer and caregivers.

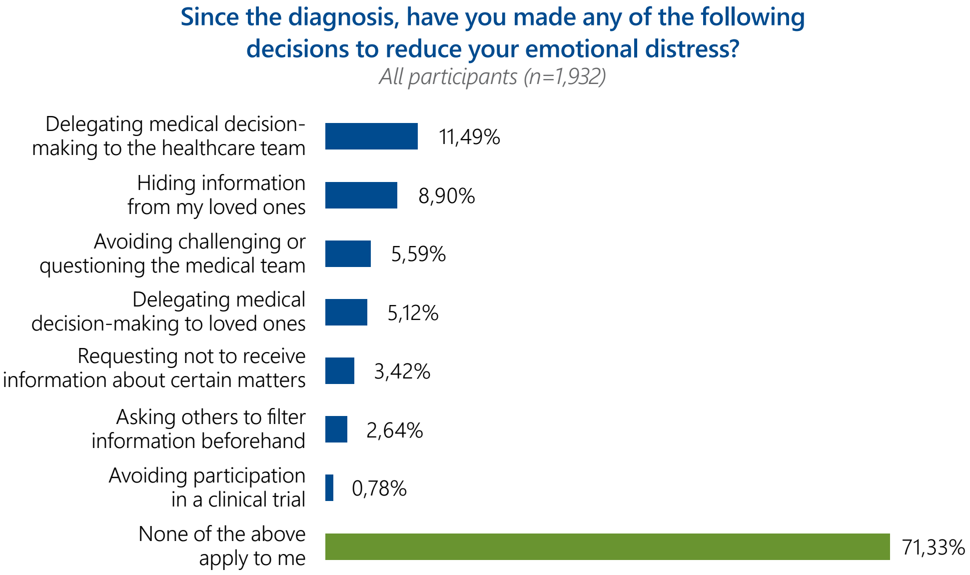
Since the diagnosis, have you made any of the following decisions to reduce your emotional distress?
All participants (n=1,932)

Figure 20. *Decisions undertaken since the diagnosis to reduce emotional distress.*

Since the diagnosis, have you made any of the following decisions to reduce your emotional distress? *Comparison between patients and caregivers*

	People with LC (n=1,536)	Caregivers (n=396)
Avoiding participation in a clinical trial	0.65%	1.26%
Asking others to filter information beforehand	2.28%	4.04%
Requesting not to receive information about certain matters	3.19%	4.29%
Delegating medical decision-making to loved ones	3.65%	10.86%
Avoiding challenging or questioning the medical team	5.53%	5.81%
Hiding information from my loved ones	8.27%	11.36%
Delegating medical decision-making to the healthcare team	10.35%	15.91%
None of the above apply to me	73.57%	62.63%

Table 29. *Decisions taken since the diagnosis to reduce emotional distress (patients vs. caregivers)*

Another challenge identified in our survey is that **44.53% of survey participants did not feel well equipped to manage the emotional impact of lung cancer.** In Figure 21, we observed that only 13.99% felt *very much* capable, while 41.48% felt *quite a bit* capable. Table 30 shows that a high level of capability was more frequently reported by individuals diagnosed with lung cancer compared to caregivers (59.83% *vs.* 40.33%).

These results showed a statistically significant difference between women and men. **Male participants felt more capable of managing the emotional impacts of lung cancer than women[*].** A total of 63.95% of men stated that they had felt highly capable of managing these repercussions, compared to 53.71% of women. While the difference is not large, it is statistically significant and highlights a gender-based disparity in emotional coping capacities following a cancer diagnosis.

Groups that reported being less capable of managing the emotional repercussions: caregivers, women, and younger participants.

It is also notable that our results show a statistically significant difference between younger (aged 18-64) and older patients (aged over 64) in their self-reported ability to manage the emotional consequences of lung cancer. **Participants aged 64 or younger reported feeling less capable of coping with the emotional impact of the disease** compared to those aged 65 and older[**]. This difference may reflect variations in coping mechanisms, life experience, or access to support systems between the two age groups.

To what extent have you felt capable of managing the emotional repercussions of lung cancer?

All participants (n=2,194)

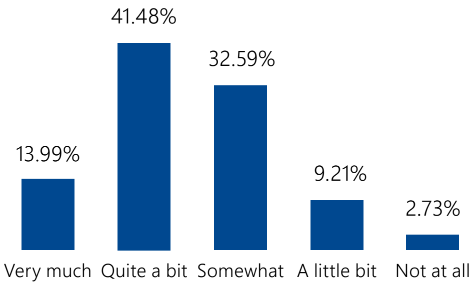

Figure 21. *Self-reported ability to manage emotional repercussions of lung cancer.*

To what extent have you felt capable of managing the emotional repercussions of lung cancer? *Comparison between patients and caregivers*

	People with LC (n=1,703)	Caregivers (n=491)
Very much	15.97%	7.13%
Quite a bit	43.86%	33.20%
Somewhat	30.24%	40.73%
A little bit	7.57%	14.87%
Not at all	2.35%	4.07%

Table 30. *Self-reported ability to manage emotional repercussions of lung cancer (patients vs. caregivers)*

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[*] t(2155) = 4.4149, p < .001. Cohen's d = 0.23.

[**] t(2152) = 5.96, p < .001. Cohen's d = 0.28.

Only 4 in 10 frequently expressed their feeling with their loved ones.

While this survey revealed significant mental health needs among people impacted by lung cancer, and the importance of support from loved ones, it is noteworthy that—as shown in Figure 22—a considerable group of respondents did not usually share their emotions or feelings with their loved ones.

Only 39.15% of respondents reported expressing their feelings often or always. Notably, **nearly 1 in 4 (23.03%) stated that they rarely or never shared their emotions.** Table 31 shows no differences between patients and caregivers in this regard.

> *Loneliness is the hardest to manage. I don't know how to ask for help.*
> *I shut down when I feel lost.* *(Person with lung cancer from Spain)*

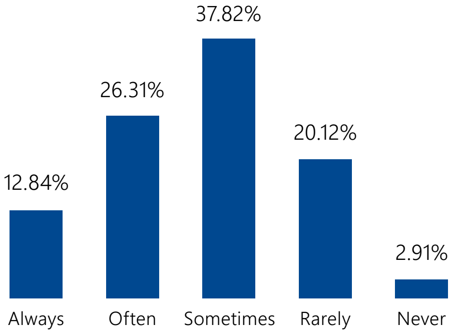

To what extent have you expressed your feelings to those around you?
All participants (n=2,197)

Figure 22. *Extent of expressing feelings to those around participants.*

To what extent have you expressed your feelings to those around you?*Comparison between patients and caregivers*

	People with LC (n=1,705)	Caregivers (n=492)
Always	13.43%	10.77%
Often	25.81%	28.05%
Sometimes	37.77%	38.01%
Rarely	20.18%	19.92%
Never	2.82%	3.25%

Table 31. *Extent of expressing feelings to those around participants (patients vs. caregivers)*

Previous research has shown that a lack of social support may increase perceptions of burden and, in turn, levels of depression[33]. According to our survey, **only 58.91% of participants reported that they always had someone to help them when needed** (Figure 23), with people with lung cancer (61.02%) slightly more likely to report this than caregivers (50.73%) (Table 32).

Only 6 in 10 respondents always had someone to help when needed, with men reporting better support than women.

Our results indicate that 25.33% participants did not have someone to help every time they needed, and an additional 11.11% did not always ask for help.

The results revealed a statistically significant difference between women and men on this issue. **Men were more likely than women to report having someone they could rely on when they needed help the most[*].** A total of 67.55% of males indicated they had someone to support them, compared to 56.39% of female respondents. Notably, a higher proportion of women reported that they had someone available, but did not always ask for help, compared to men (12.40% *vs.* 6.01%).

Do you have someone who can help you when you need it most?
All participants (n=1,998)

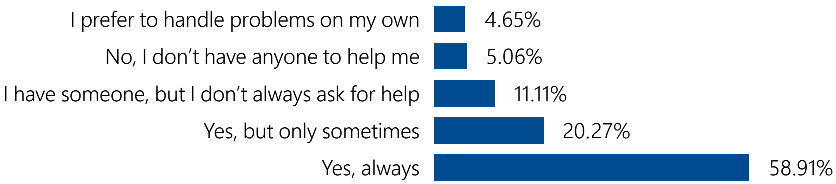


Figure 23. *Availability of support when needed most.*

Do you have someone who can help you when you need it most?
Comparison between patients and caregivers

	People with LC (n=1,588)	Caregivers (n=410)
Yes, always	61.02%	50.73%
Yes, but only sometimes	19.27%	24.15%
I have someone, but I don't always ask for help	10.39%	13.90%
No, I don't have anyone to help me	4.91%	13.90%
I prefer to handle problems on my own	4.41%	5.61%

Table 32. *Availability of support when needed most (patients vs. caregivers)*

> *I'm not lonely, but I have much less contact with others.*
> *(Person with lung cancer from The Netherlands)*

> *I sometimes find myself alone in facing my husband's physical and emotional pain.*
> *(Caregiver from Italy)*

> *People I considered friends all disappeared. They don't want problems, nor to help.*
> *(Person with lung cancer from Portugal)*

---

[*] t (1971) = 3.8214, p < .001. Cohen's d = 0.21.

Figure 24 shows that while most participants reported having some level of contact or relationship with family or friends, they also identified some challenges in the support they received. The most frequently cited issue was that **those around them did not fully understand what they were going through** (65.54%).

65% reported feeling misunderstood by the people around them.

Notably, one in four participants reported that they did not share their concerns with loved ones (26.45%), and nearly as many felt that the **support they received was not aligned with their needs** (24.16%).

Table 33 shows no differences between patients and caregivers in this regard.

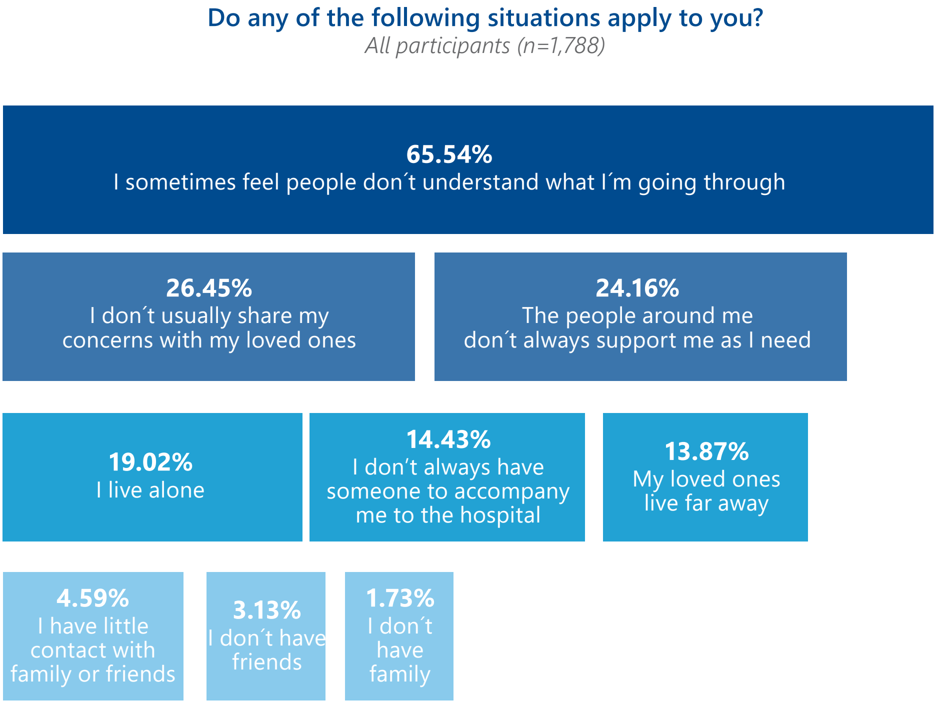


Figure 24. *Symptoms of loneliness.*

Do any of the following situations apply to you?
Comparison between patients and caregivers

	People with LC (n=1,419)	Caregivers (n=396)
I sometimes feel people don´t understand what I´m going through	64.48%	64.77%
I don´t usually share my concerns with my loved ones	27.13%	23.85%
The people around me don´t always support me as I need	23.47%	26.83%
I live alone	22.69%	4.88%
I don't always have someone to accompany me to the hospital	15.86%	8.94%
My loved ones live far away	13.32%	15.99%
I have little contact with family or friends	4.23%	5.96%
I don´t have friends	3.03%	3.52%
I don´t have family	1.90%	1.08%

Table 33. *Symptoms of loneliness (patients vs. caregivers)*

> *Found family/friends said they would help but when asked don't. Husband does all the help as well as trying to work to support us.*
> *(Person with lung cancer from The United Kingdom)*
>
> *When I talk about it, some people, including close ones, don't understand the almost constant pain, the feeling of losing parts of my intellect, memory, and thus identity.*
> *(Person with lung cancer from France)*
>
> *With targeted therapies, we look fine physically. Others don't see what we endure. It feels like we're bothering them with our issues.*
> *(Person with lung cancer from France)*
>
> *I don't want to be a burden to my loved ones.*
> *(Person with lung cancer from Spain)*
>
> *I don't like burdening others, especially my child.*
> *(Caregiver from Croatia)*
>
> *I mask and hide a lot, partly because I don't want to be a burden and because I feel it is expected of me.*
> *(Person with lung cancer from Ireland)*
>
> *Difficulty having a friend available to help attend appointments.*
> *(Person with lung cancer from Portugal)*
>
> *I struggle to ask for help in my darkest moments because I expected help from my family without needing to ask.*
> *(Caregiver from Italy)*

Given the significant impact of lung cancer on mental health, screening and support for psychological distress—or even mental health disorders—should be implemented as part of care[34]. However, as shown in Table 34, **50.53% of respondents reported not being offered any form of mental health support*.** This need is particularly pronounced among caregivers. Only 53.05% were informed about mental health supports, compared to 66.66% of people diagnosed with lung cancer.

According to our 7th LuCE Report (2022), most people impacted by lung cancer wanted to be informed about the supportive services available at the time of receiving the news of a lung cancer diagnosis[9]. Assessment of emotional problems at the time of diagnosis provides opportunities for early intervention to help mitigate the impact of emotional problems over time[35]. However, our current survey shows that **only 28.68% received information about mental health services at the time of diagnosis.**

> *Access to mental health support would have been useful at diagnosis, but now 28 months on, I have found my own way.*
> *(Person with lung cancer from The United Kingdom)*
>
> *I was not referred to the hospital psychologist when I was diagnosed, I think I should have been but have been referred to them recently after recurrence.*
> *(Person with lung cancer from Ireland)*

Other participants were informed at different stages of the disease (during treatment: 27.82%; after treatment: 7.11%), highlighting the importance not only of offering this information, but also of providing it at an earlier stage of the care pathway, based on each person's needs and preferences.

As part of your care pathway, were you offered any mental health support in relation to your lung cancer diagnosis?

	All participants (n=2,193)	People with LC (n=1,701)	Caregivers (n=492)
No	31.24%	27.87%	42.89%
No, but I sought this out myself	19.29%	19.28%	19.31%
Yes, after the treatment	7.11%	7.05%	7.32%
Yes, while receiving treatment	27.82%	29.22%	22.97%
Yes, at the time of diagnosis	28.68%	30.39%	22.76%

Table 31. *Extent of expressing feelings to those around participants (patients vs. caregivers)*

---

* `No´ (31.24%) + `No, but I sought this out myself´ (19.29%)

4 in 10 did not report their emotional difficulties to their healthcare team.

This study also finds that limited access to mental health support is not solely due to a lack of provision by healthcare providers; patients and caregivers also tended not to communicate their emotional difficulties. **Almost 4 in 10 participants acknowledged experiencing emotional difficulties but did not report them to their healthcare team** (Figure 25). Notably, as shown in Table 35, caregivers were more likely than patients to withhold sharing these issues (49.70% *vs.* 36.47%).

Our research shows that **women were significantly more likely than male respondents to report emotional difficulties** to their healthcare team*. While 39.71% of women had talked with their healtcare professionals, this percentage dropped to 29.23% among men.

Additionally, **participants impacted by advanced lung cancer** were significately more likely to report emotional difficulties than those with early-stage disease**. **Older adults (aged over 65)** also reported communicating emotional difficulties to their healthcare team more often than younger participants (aged 18-64)***. This highlights a gap in communication that could impact emotional care and suggests a need to create safer, more approachable environments for younger adults to express emotional concerns.

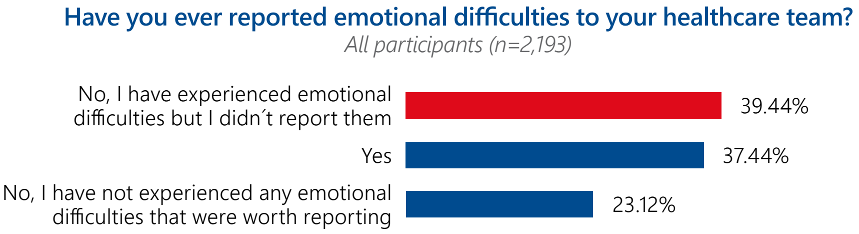


Figure 25. *Reporting emotional difficulties to healthcare team.*

Have you ever reported emotional difficulties to your healthcare team?
Comparison between patients and caregivers

	People with LC (n=1,700)	Caregivers (n=493)
No, I have experienced emotional difficulties but I didn´t report them	36.47%	49.70%
Yes	38.76%	32.86%
No, I have not experienced any emotional difficulties that were worth reporting	24.76%	17.44%

Table 35. *Reporting emotional difficulties to healthcare team (patients vs. caregivers)*

---

* t(2153) = −6.0115, p < .001. Cohen's d = −0.31. ** t(2130) = −4.018, p < .001. Cohen's d = −0.19.
*** t(2150) = -7.85, p < .001. Cohen's d = -0.37.

Most participants reported not being open to seeking professional support.

Our findings suggest that a majority of those impacted by lung cancer are often reluctant to seek professional mental health care. **Only 47.66% of respondents stated that they have always been open to seeking professional support** (Figure 26). The main reasons given for avoiding such support were a preference for handling things on their own (20.33%) and not perceiving a strong need for support (19.22%).

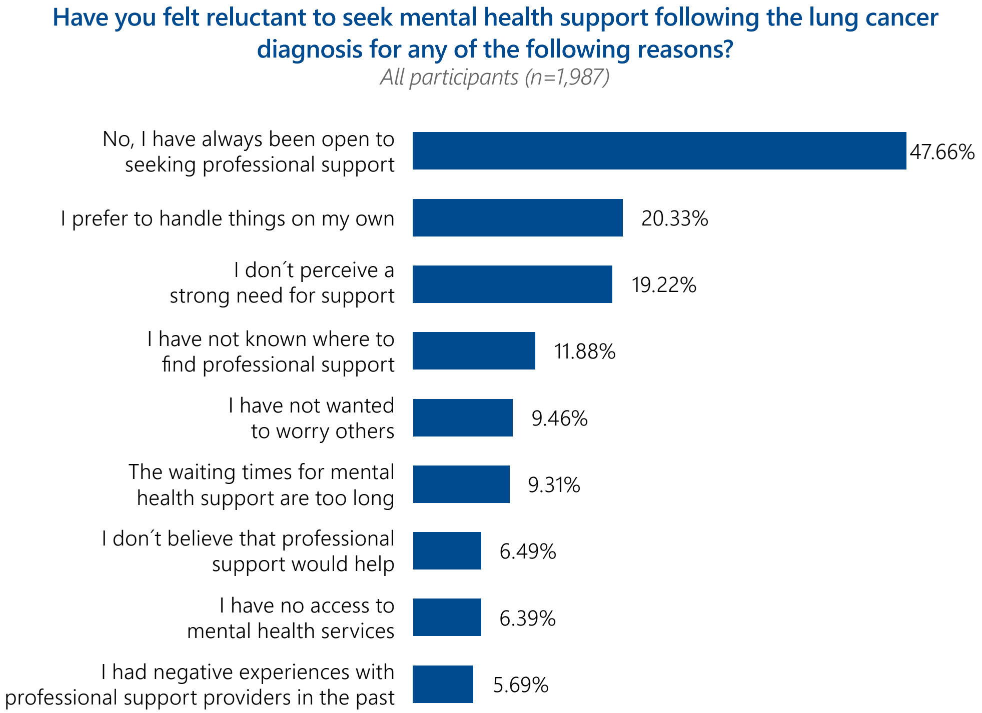


Figure 26. *Reluctance to seek mental health support following lung cancer diagnosis.*

> *I can't afford private mental health care, and in public hospitals you can't get clear answers or suitable doctors.*
> *(Person with lung cancer from Greece)*

> *I was the only caregiver and didn't think of it at all. My mother was my top priority.*
> *(Caregiver from The Netherlands)*

> *My oncologist is great, but I don't always feel comfortable saying what I want.*
> *(Person with lung cancer from The United Kingdom)*

> *I don't believe that a random psych nurse or psychologist would understand my situation.*
> *(Caregiver from Finland)*

Table 36 illustrates slight differences between those with lung cancer and their caregivers when it comes to openness and barriers to seeking professional mental health support. Patients were more likely to report being open to seeking professional help (48.86% *vs.* 42.93%), while caregivers more frequently cited barriers such as not knowing where to find support (15.38% *vs.* 10.98%) and not wanting to worry others (13.90% *vs.* 8.33%).

Have you felt reluctant to seek mental health support following the lung cancer diagnosis for any of the following reasons? *Comparison between patients and caregivers*

	People with LC (n=1,584)	Caregivers (n=403)
No, I have always been open to seeking professional support	48.86%	42.93%
I prefer to handle things on my own	20.14%	21.09%
I don´t perceive a strong need for support	20.52%	14.14%
I have not known where to find professional support	10.98%	15.38%
I have not wanted to worry others	8.33%	13.90%
The waiting times for mental health support are too long	9.22%	9.68%
I don´t believe that professional support would help	5.68%	9.68%
I have no access to mental health services	5.62%	9.43%
I had negative experiences with professional support providers in the past	5.93%	4.71%

Table 36. *Reluctance to seek mental health support following lung cancer diagnosis (patients vs. caregivers)*

> *I always struggled asking for help, afraid of being seen as a burden.*
> *(Person with lung cancer from The Netherlands)*

> *I didn't want support right after diagnosis, only about a year later, but then I couldn't find a psycho-oncologist.*
> *(Person with lung cancer from Germany)*

> *I didn't have the energy to seek support, even though I looked into different options.*
> *(Person with lung cancer from Finland)*

> *Learning to open up to help. I thought I could do it alone, but reality is different.*
> *(Caregiver from Finland)*

> *Before the diagnosis I was sceptical about psychotherapy, but I realized afterwards that support was essential.*
> *(Person with lung cancer from Italy)*

Attitudes toward mental health and trust in support services may influence whether someone actively seeks help. As illustrated in Figure 27, **most participants (83.67%) placed a high value on mental health, recognizing its influence on lung cancer treatment outcomes.** Consequently, people impacted by lung cancer not only emphasised the importance of caring for mental health as part of overall well-being, but also as an essential component of the clinical journey.

A similar percentage also stated that **good mental health requires a positive attitude** (82.10%). While some studies have found that maintaining a positive attitude does not influence survival rates or the progression of the disease, others suggest that optimism and a positive outlook can significantly enhance the quality of life for people living with cancer[36].

Our survey revealed some misperceptions or misunderstandings around mental health support. Only 75% of participants disagreed with the statement that seeking emotional support is only for those who cannot handle things on their own. Additionally, 23.07% of respondents thought that medications for emotional distress might interfere with lung cancer treatment. These two concerns could negatively influence a proactive approach to seeking mental health support when needed.

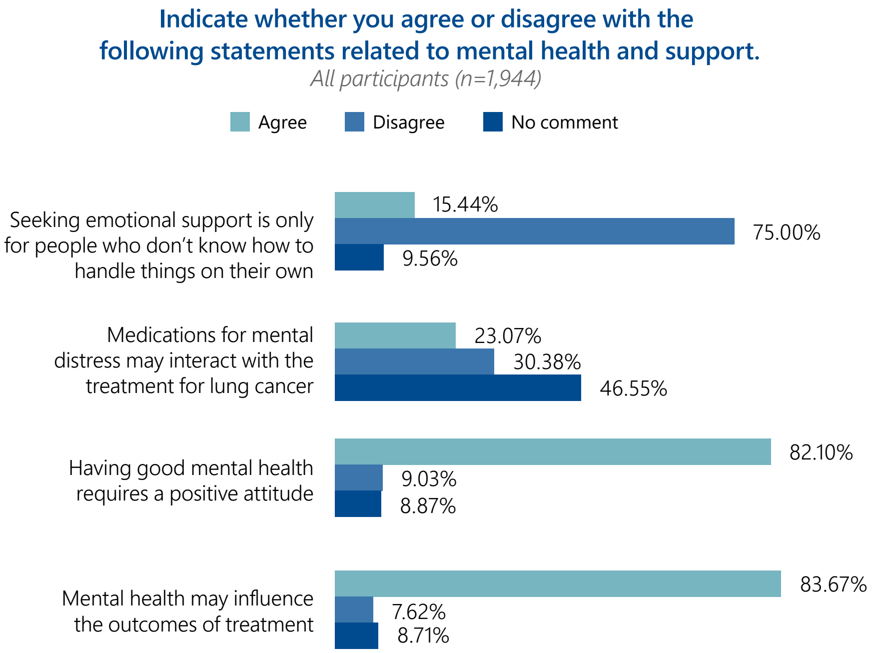


Figure 27. *Agreement with statements related to mental health and support.*

According to Table 37, both patients and caregivers reported similar perceptions regarding mental health and support.

Indicate whether you agree or disagree with the following statements related to mental health and support.
Comparison between patients and caregivers

People with LC (n=1,544)	Agree	Disagree	No comment
Seeking emotional support is only for people who don't know how to handle things on their own	14.95%	76.01%	9.04%
Medications for mental distress may interact with the treatment for lung cancer	23.50%	29.70%	46.80%
Having good mental health requires a positive attitude	82.28%	8.83%	8.89%
Mental health may influence the outcomes of treatment	83.13%	8.18%	8.70%

Caregivers (n=400)	Agree	Disagree	No comment
Seeking emotional support is only for people who don't know how to handle things on their own	17.34%	71.11%	11.56%
Medications for mental distress may interact with the treatment for lung cancer	21.41%	33.00%	45.59%
Having good mental health requires a positive attitude	81.41%	9.80%	8.79%
Mental health may influence the outcomes of treatment	85.75%	5.50%	8.75%

Table 37. *Agreement with statements related to mental health and support (patients vs. caregivers).*

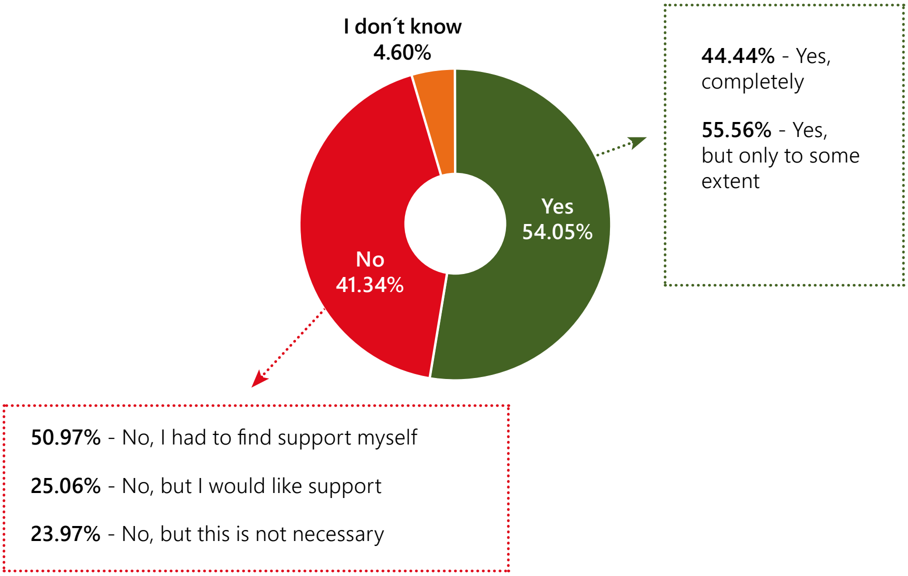
4 in 10 felt their healthcare team did not provide adequate emotional support.

The healthcare team includes various professionals whose mission is to provide comprehensive support and treatment to people impacted by lung cancer, addressing medical, physical, social, emotional, and spiritual needs. However, **41.34% of participants stated that they did not feel that their healthcare team had given appropriate emotional support** (Figure 28). Half (50.97%) had to find support themselves, 25.06% would have liked support, and 23.97% did not consider it necessary. Regarding this last group, it is important to note that even if a person does not require emotional support at a given time, healthcare teams should remain ready to support patients and caregivers with empathy and compassion.

Only 54.05% felt emotionally supported by their healthcare team, and a majority (55.56%) indicated that this support was only to some extent. These findings highlight a **significant gap in emotional care** and point to the need for a more proactive and systematic approach to psychosocial support within healthcare settings.

Do you feel your healthcare team has given you appropriate emotional support to help you manage the disease?

All participants (n=1,998)



44.44% - Yes, completely

55.56% - Yes, but only to some extent

50.97% - No, I had to find support myself

25.06% - No, but I would like support

23.97% - No, but this is not necessary

Figure 28. *Perceived adequacy of emotional support from healthcare team.*

Table 38 shows data comparing patients and caregivers, revealing statistically significant differences between the groups. **People diagnosed with lung cancer reported receiving more appropriate emotional support from their healthcare teams** than caregivers did[*]. One in four patients (25.22%) reported receiving complete emotional support, compared to 19.42% of caregivers. Additionally, 31.72% of patients felt supported to some extent, *vs.* 23.54% of caregivers.

The data highlights a significant emotional support gap, especially among caregivers, who often have substantial responsibilities and duties but may be less likely to receive or seek help.

Do you feel your healthcare team has given you appropriate emotional support to help you manage the disease? *Comparison between patients and caregivers*

	People with LC (n=1,586)	Caregivers (n=412)
Yes, completely	25.22%	19.42%
Yes, but only to some extent	31.72%	23.54%
No, but I would like support	9.65%	13.11%
No, I had to find support myself	20.49%	23.30%
No, but this is not necessary	9.71%	10.68%
Don't know / not sure	3.22%	9.95%

Table 38. *Perceived adequacy of emotional support from healthcare team (patients vs. caregivers)*

---

[*] t(5.4571, df = 1996, $p < 0.001$. Cohen's d = 0.30.

Patient organisations and non-profit organisations (NGOs) have become increasingly active in recent years. They can help the patient and caregiver engage more effectively with their care team and in their own care and provide psychosocial support[32]. In our 9th LuCE Report (2024), half of the participants reported receiving information about lung cancer through patient organisations[37].

Most participants were not informed about patient organisations by healthcare providers.

However, our current study indicates that there is room for improvement in the information provided by healthcare professionals regarding patient organisations and NGOs. A total of **65.88% of respondents reported not receiving any information about these entities from their healthcare providers,** and only 17.54% were informed at the time of diagnosis (Figure 29).

Table 39 presents a comparison between responses from patients and caregivers, showing no differences. The only finding is that patients were slightly more likely than caregivers to have received information from the healthcare teams about patient organisations (44.68% *vs.* 35.42%).

Have you ever been referred to patient organisations or non-profit organisations by a healthcare provider?
All participants (n=2,195)

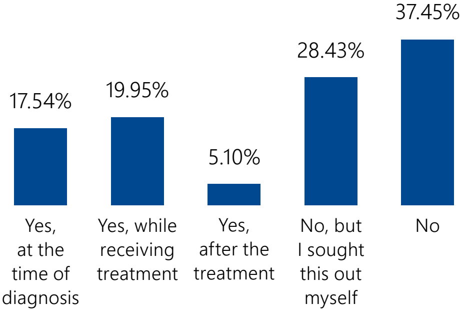


Figure 29. *Referral to patient or non-profit organisations by healthcare providers.*

Have you ever been referred to patient organisations or non-profit organisations by a healthcare provider? *Comparison between patients and caregivers*

	People with LC (n=1,701)	Caregivers (n=494)
Yes, at the time of diagnosis	18.17%	15.38%
Yes, while receiving treatment	21.63%	14.17%
Yes, after the treatment	4.88%	5.87%
No, but I sought this out myself	29.69%	24.09%
No	34.04%	49.19%

Table 39. *Referral to patient or non-profit organisations by healthcare providers (patients vs. caregivers)*

The findings of this report highlight the importance of the support received by loved ones. Informal caregivers, such as family or friends, are the primary source of support for people diagnosed with cancer[4]. Figure 30 emphasizes this point, showing that **the vast majority of participants reported receiving informal support** (93.58%), and **most participants were satisfied with the emotional support received** (82.51%).

The second most frequently cited source of emotional support satisfaction was the **healthcare team** (64.57%). However, it is remarkable that **1 in 3 participants were either unsatisfied or stated that they did not receive this type of support** at all.

Importantly, this study also finds that most participants who received peer support or assistance from patient organisations or NGOs reported being satisfied with the emotional support received. This data highlights the importance of improving the information about these entities within the healthcare setting.

Support from peers and patient organisations was valued positively by those who accessed them.

Significant differences were found in satisfaction with support from psychologists*, patient organisations**, peer support***, and family/loved ones****, where patients with advanced lung cancer (Stage III-IV) reported lower satisfaction compared to those in early stages (Stage I-II).

Level of satisfaction with the support received to cope with the emotional impact of lung cancer.

All participants (n=1,999)

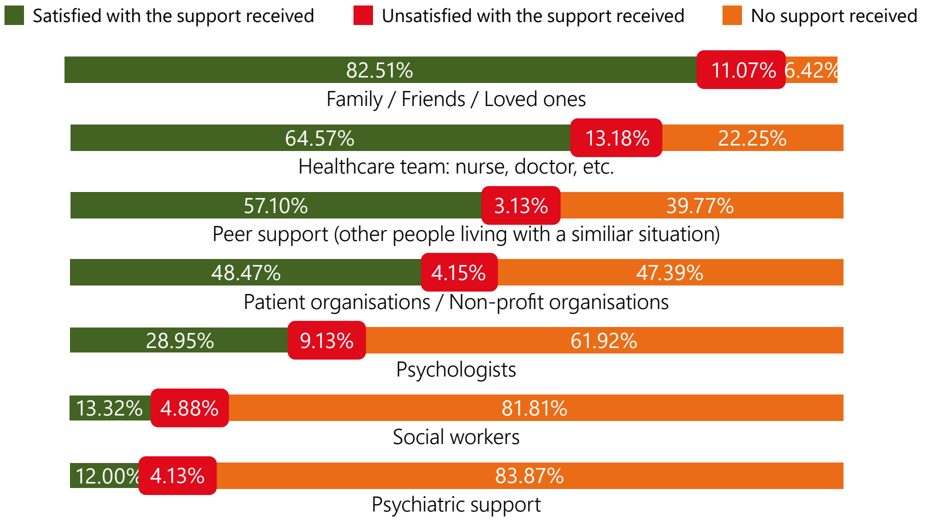


Figure 30. *Level of satisfaction with support received to cope with the emotional impact of lung cancer.*

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* t(1817) = −4.32, p < .001. Cohen's d = −0.23. ** t(1813) = −4.91, p < .001. Cohen's d = −0.26.
*** t(1809) = −4.20, p < .001. Cohen's d = −0.22. **** t(1930) = −2.39, p = .017. Cohen's d = −0.12.

Both patients and caregivers reported high levels of satisfaction with the emotional support provided by loved ones, with both groups considering this the most satisfying source of emotional support.

Patients were more satisfied with the emotional support received from the healthcare team (67.32% *vs.* 54.00%), while caregivers more frequently reported receiving no support at all from these professionals (32.75% *vs.* 19.52%). Additionally, patients were more likely to receive emotional support provided by peers (63.20% *vs.* 49.10%), as well as from patient organisations or non-profit organisations (55.54% *vs.* 41.45%).

Level of satisfaction with the support you have received to cope with the emotional impact of lung cancer *Comparison between patients and caregivers*

People with LC (n=1,589)			
	Satisfied with the support received	Unsatisfied with the support received	No support received
Family / Friends / Loved ones	83.08%	11.01%	5.92%
Healthcare team: nurse, doctor, etc.	67.32%	13.16%	19.52%
Peer support	60.26%	2.94%	36.80%
Patient organisations / Non-profit organisations	51.19%	4.35%	44.46%
Psychologists	29.64%	9.99%	60.37%
Social workers	13.99%	4.66%	81.35%
Psychiatric support	11.75%	4.62%	83.64%
Caregivers (n=410)			
	Satisfied with the support received	Unsatisfied with the support received	No support received
Family / Friends / Loved ones	80.30%	11.33%	8.37%
Healthcare team: nurse, doctor, etc.	54.00%	13.25%	32.75%
Peer support	45.27%	3.84%	50.90%
Patient organisations / Non-profit organisations	38.08%	3.37%	58.55%
Psychologists	26.34%	5.88%	67.77%
Social workers	10.82%	5.67%	83.51%
Psychiatric support	12.95%	2.33%	84.72%

Table 40. *Level of satisfaction with support received to cope with the emotional impact of lung cancer (patients vs. caregivers).*

Satisfied thanks to the ALK+ROS1 association, which let me talk with patients with the same cancer and gene. ***(Person with lung cancer from France)***

Finding the EGFR UK Positive charity & Facebook group has been amazing. ***(Person with lung cancer from The United Kingdom)***

I received significant psychological support from my parish priest. ***(Caregiver from Greece)***

No one gave me support in healthcare, only my family! ***(Person with lung cancer from Croatia)***

The information provided by patient associations like AEACaP is very useful to me. ***(Person with lung cancer from Spain)***

I'm lucky I was able to get psychological help very quickly on my own. That's crucial in the first panicky weeks! ***(Person with lung cancer from The Netherlands)***

Healthcare staff take care of the physical side of cancer treatment, but they don't have time for anything else. ***(Person with lung cancer from Denmark)***

Relatives struggle to understand the situation and therefore to help. ***(Person with lung cancer from France)***

Depite the substantial distress that can be associated with a cancer diagnosis and treatment, many people impacted by cancer manifest remarkable resilience, and some studies have shown that overcoming cancer and treatment can result in personal growth and satisfaction with oneself when coping with disease related demands[38].

As illustrated in Table 41, **feeling comforted by the support received from loved ones was cited as the most rewarding and positive aspect** experienced since the lung cancer diagnosis (67.45%). The second most mentioned aspect (57.95%) related to **care and support from the healthcare team,** with a higher proportion among patients compared to caregivers (60.57% *vs.* 47.80%).

The next two most cited aspects were linked to personal attributes that promote psychological adaptation to lung cancer: **learning to appreciate life in a new way** (54.00%) and **feeling proud of how they were coping with the disease** (50.85%). Both aspects were reported more often by patients than by caregivers.

Since the lung cancer diagnosis, have you experienced any of the following rewarding or positive aspects?			
	All participants (n=2,000)	People with LC (n=1,590)	Caregivers (n=410)
Feeling comforted by the support received from family, friends, etc.	67.45%	69.31%	60.24%
Satisfaction with the care received from the healthcare team	57.95%	60.57%	47.80%
Learning to appreciate life in a new way	54.00%	56.48%	44.39%
Feeling proud of how I have coped since the diagnosis	50.85%	55.85%	31.46%
Developing greater closeness and affection with loved ones	34.25%	33.46%	37.32%
Making life changes that align more with what I truly want	26.45%	29.50%	14.63%
Having the opportunity to help others	26.10%	27.17%	21.95%
None	4.75%	3.52%	9.51%

Table 41. *Rewarding and positive experiences reported since lung cancer diagnosis.*

Discovering a wonderful cancer support community who have improved my quality of life and wellbeing. ***(Person with lung cancer from The United Kingdom)***

I developed the desire to help other cancer patients because I don't want anyone to go through what we experienced. ***(Caregiver from Greece)***

Being able to spend meaningful time with the person who has lung cancer provides me with joy and gratitude. ***(Caregiver from Ireland)***

The moment of diagnosis was terrible. But reacting and living as much as we can is my best weapon. Every day I am grateful to be able to live for my grandchildren. ***(Person with lung cancer from Hungary)***

I feel joy and satisfaction from small, good everyday experiences and am grateful for every day without discomfort like biopsies, hospital visits, etc. ***(Person with lung cancer from Norway)***

The Lung Cancer Association supported my family during diagnosis. After I gained strength, I became active in the association, and today I'm one of its mentors. ***(Person with lung cancer from Israel)***

I'm working on setting priorities. There's more honesty in conversations. ***(Caregiver from Ukraine)***

I try to move slowly to truly perceive everything. ***(Person with lung cancer from Germany)***

Learning to tell people I love them. ***(Person with lung cancer from France)***

It brought me closer again to my husband. ***(Person with lung cancer from France)***

Measures proposed to improve mental health: medical information and support with side effects.

Nearly half of the participants (49.38%) reported that having **more information about the disease, and treatment and care options** were key to improving mental health. Our research suggests that hopelessness is a significant cause of psychological distress. Receiving information and perceiving greater treatment and care options fosters hope and a sense of control among the survey respondents.

According to 43.90% of respondents, mental health could be improved by receiving more **assistance in managing side effects.** This issue has been highlighted in previous LuCE reports and emphasizes the need for better support to improve the mental health of those impacted by lung cancer.

These findings highlight the importance of improving and personalising communication and providing appropriate information to patients and caregivers. Specifically, **better communication with healthcare professionals** was identified as the third most important factor to improving their mental health, according to 37.59% of participants. This need was reported more frequently by caregivers (44.80%) than by patients (35.71%). Consistent with these findings, the 9th LuCE Report revealed that caregivers lacked more information (42.6% *vs.* 28.7% in patients) and experienced poor communication with the healthcare team (36.4% *vs.* 24.6%)[37].

Which of the following measures do you think could help improve your mental health?	All participants (n=1,950)	People with LC (n=1,546)	Caregivers (n=404)
More information about the disease, treatment and care options	49.38%	48.25%	53.71%
Support to deal with side effects	43.90%	44.24%	42.57%
Better communication with healthcare professionals	37.59%	35.71%	44.80%
Access to mental health services	34.36%	31.57%	45.05%
Peer support (other people living with a similar situation)	30.41%	30.85%	28.71%
Support to deal with financial and work-related repercussions	29.74%	28.59%	34.16%
Digital resources (apps, websites, etc.)	15.95%	15.98%	15.84%
Access to palliative care	15.90%	13.32%	25.74%

Table 42. *Perceived helpful measures to improve mental health.*

The progress of my administrative files takes an enormous amount of energy over very long periods, often without significant progress. There's always something to do or renew, which is exhausting because we are alone. ***(Person with lung cancer from France)***

My doctor is great, but I didn't like the coordinating nurse, and I had to figure out a lot on my own. I found my own rehab program, where I got psychological support. ***(Person with lung cancer from The Netherlands)***

Psychological support should be standard after diagnosis. ***(Person with lung cancer from The Netherlands)***

More information about possible side effects my sister's medication could cause, and what my role is as a close person: how to support, how to set boundaries, when to intervene... ***(Caregiver from Finland)***

After diagnosis, patients should be immediately offered professional psychological help, group therapy... I was not offered that. ***(Person with lung cancer from Croatia)***

Less stigma from the assumption the cancer is tobacco-related. ***(Person with lung cancer from The United Kingdom)***

I understand oncologists, pulmonologists, professors don't have time to explain everything, but it would be good to have an assistant to answer our questions. ***(Person with lung cancer from France)***

I would really like palliative care to be organized: one dedicated professional, a link between GP and specialists... now it's fragmented and very difficult. ***(Person with lung cancer from The Netherlands)***

In Slovenia, palliative care is very poor, except a few ones. ***(Caregiver from Slovenia)***

Dealing with side effects of cancer treatment is also part of the picture. This can have a much bigger effect on mental health but is not considered important as the person is meant to be grateful the cancer is under control despite any debilitating effects of treatment. ***(Person with lung cancer from Ireland)***

Access to mental health support for my partner & I as a unit. Rather than seeking individual support. ***(Person with lung cancer from The United Kingdom)***

More time with oncologists and more empathy (training for them). ***(Person with lung cancer from Spain)***

By being listened to, as I have picked up changes in my partner quicker than his team but have not really been listened to. ***(Caregiver from The United Kingdom)***

Support to continue maintaining a healthy lifestyle over time. ***(Person with lung cancer from Italy)***

4. Call to action

No one should have to face lung cancer alone

Healthcare systems, and policymakers must recognise mental health support as a fundamental part of the lung cancer care pathway.

The emotional impact of lung cancer deeply disrupts the daily lives of people living with the disease and those in a caregiving capacity. Yet, too many individuals impacted by lung cancer do not receive mental health support, and many struggle in silence. It is essential that psychosocial services be proactively offered at every stage of the lung cancer care pathway, with trained professionals available to provide emotional care and counselling alongside medical treatment.

Healthcare professionals must provide clear information and empower individuals to manage their disease and mental well-being.

Patients and caregivers consistently report the need for more medical information, guidance to manage side effects, and improved communication with healthcare professionals to actively improve their mental health. We call on healthcare professionals to provide clear, comprehensive information about lung cancer, available treatments and care options – so that those impacted by lung cancer can actively manage their disease and mental well-being.

5. About LuCE

Lung Cancer Europe (LuCE) is a not-for-profit umbrella organisation established in 2013 to provide a platform for lung cancer patient advocacy associations and networks at a European level.

Our vision

All Europeans impacted by or at risk of lung cancer will have access to optimal care so that they have the best possible outcomes and quality of life.

Our mission

LuCE is the voice of Europeans impacted by or at risk of lung cancer. We collaborate with members and other stakeholders to destigmatise the disease and ensure that those impacted by lung cancer get the care they need to achieve the best possible outcomes. We empower members to ensure strong and effective lung cancer patient advocacy across Europe.

Lung Cancer Europe

lungcancereurope.eu info@lungcancereurope.eu

About our members

LuCE provides a platform for organisations and individuals working for people impacted by lung cancer. As of October 2025, there are 46 members (42 organisations and 4 individuals), representing 26 countries.

Thank you all for your great support and unwavering commitment to the lung cancer community across Europe. Together, we are building a stronger, more compassionate future for all those impacted by lung cancer.

We encourage you to support and learn more about our member organisations.

www.lungcancereurope.eu/our-members

Associations

Österreichische Lungenunion
www.lungenunion.at

Association of Patients with Respiratory
Failure and Lung Transplantation

ALK Positive Belgium
www.alkpositivebelgium.be

Prolong VZW
www.prolong.be

Moje Plíce
www.mojeplice.cz

Jedra
www.jedra.toraks.hr

Patientforeningen Lungekræft
www.lungekraeft.com

Pulmones - Suomen Keuhkosyöpäyhdistys ry
www.pulmones.fi/ajankohtaista

Suomen Syöpäpotilaat
www.syopapotilaat.fi

ALK FRANCE cancer poumon
www.alkros1francecancerpoumon.wordpress.com

Patients en Reseau/Mon Reseau Cancer du Poumon
www.monreseau-cancerdupoumon.com

ALK Positive Deutschland
www.alkpositiv-deutschland.org

Landesverband Baden- Württemberg für Lungenkrebskranke und deren Angehörige e.V
www.lungenkrebs-bw.de

Bundesverband Selbsthilfe Lungenkrebs e.V.
www.bundesverband-selbsthilfe-lungenkrebs.de

zielGENau
www.zielgenau.org

Fairlife Lung Cancer Care
www.fairlifelcc.com

K.E.F.I. of Athens – Association of Cancer Patients of Athens
www.anticancerath.gr

Lélek-zet Egyesület
www.lelekzetegyesulet.hu

Irish Lung Cancer Community
www.ilcc.ie

Israel Lung Cancer Foundation
www.ilcf.org.il

Associazione Insieme per i pazienti di Oncologia Polmonare IPOP ONLUS
www.associazione-ipop.org

European School of Oncology
www.eso.net

Women Against Lung Cancer in Europe
www.womenagainstlungcancer.eu

Dzivibas Koks
www.dzivibaskoks.lv

Longkanker Nederland
www.longkankernederland.nl

Lungekreftforeningen
www.lungekreftforeningen.no

Pulmonale
www.pulmonale.pt

Federatia Asociatiilor
Bolnavilor de Cancer din Romania
www.fabc.ro

Punim plućima
www.punimplucima.rs

Društvo onkoloških bolnikov Slovenije
www.onkologija.org

Asociación Española de
Afectados de Cáncer de Pulmón
www.afectadoscancerdepulmon.com

Fundación MÁS QUE IDEAS
www.fundacionmasqueideas.org

Leben mit Lungenkrebs
www.leben-mit-lungenkrebs.ch

ETOP IBCSG Partners Foundation
www.etop.ibcsg.org

Lungcancerförening
www.lungcancerforeningen.se

ALK Positive UK
www.alkpositive.org.uk

EGFR Positive UK
www.egfrpositive.org.uk

Lung Cancer Nursing UK (LCNUK)
www.lcnuk.org

Oncogene Cancer Research
www.oncogeneresearch.org

ROS1der UK
www.ros1ders-cancer.uk

Athena Women against Cancer
www.athena-wac.com

ALK Positive Europe
www.alkpositiveeurope.org

Individual members

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Nicoleta Mitrea

Regine Deniel Ihlen

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About the LuCE Working Group

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Amgen, AstraZeneca, Bayer, Bristol Myers Squibb, Boehringer Ingelheim, Daiichi Sankyo, GenMab, Gilead, Johnson & Johnson, Lilly, Merck, MSD, Novartis, Pfizer, PharmaMar, Pierre Fabre, Regeneron, Roche, Takeda and Thermo Fisher.

6. ANNEX I.

DETAILED BREAKDOWN OF PARTICIPANT CHARACTERISTICS

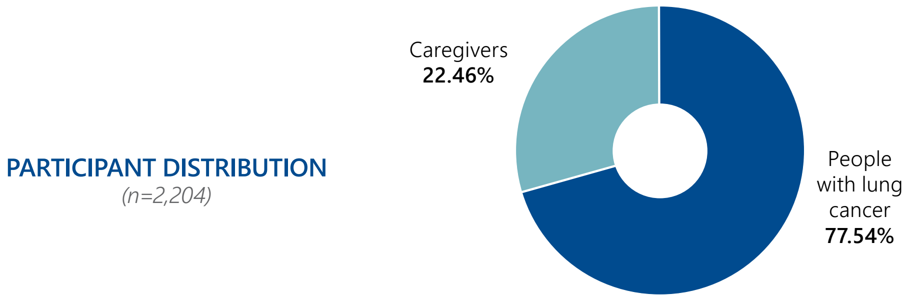

Figure 31. *Participant distribution.*

GENDER			
	All participants (n=2,180)	People with LC (n=1,691)	Caregivers (n=489)
Female	78.35%	77.29%	82.00%
Male	21.01%	22.29%	16.56%
Non-binary	0.14%	0.06%	0.41%
Prefer not to say	0.50%	0.35%	1.02%
Prefer to self-describe	0.00%	0.00%	0.00%

Table 43. *Gender.*

AGE			
	All participants (n=2,179)	People with LC (n=1,688)	Caregivers (n=491)
18 - 24	0.46%	0.18%	1.43%
25 – 34	2.57%	1.01%	7.94%
35 – 44	8.81%	5.27%	20.98%
45 – 54	21.71%	20.32%	26.48%
55 – 64	35.89%	39.10%	24.85%
65 – 74	24.23%	27.13%	14.26%
75 or older	6.33%	6.99%	4.07%

Table 44. *Age.*

LEVEL OF EDUCATION			
	All participants (n=2,176)	People with LC (n=1,684)	Caregivers (n=492)
Less than primary education	0.28%	0.24%	0.41%
Primary or lower secondary education	6.94%	7.48%	5.08%
Upper secondary / Post-secondary education	35.66%	37.05%	30.89%
Tertiary education	57.12%	55.23%	63.62%

Table 45. *Level of education.*

COUNTRY OF RESIDENCE				
		All participants (n=2,204)	People with LC (n=1,709)	Caregivers (n=495)
1	France	17.20%	20.89%	4.44%
2	United Kingdom	16.97%	18.43%	11.92%
3	The Netherlands	11.25%	12.35%	7.47%
4	Germany	8.62%	8.89%	7.68%
5	Greece	6.62%	3.51%	17.37%
6	Spain	5.67%	5.56%	6.06%
7	Ukraine	5.31%	3.69%	10.91%
8	Italy	4.95%	5.15%	4.24%
9	Croatia	4.36%	3.34%	7.88%
10	Hungary	2.36%	2.40%	2.22%
11	Finland	2.22%	2.11%	2.63%
12	Belgium	2.18%	2.28%	1.82%
13	Portugal	2.09%	1.46%	4.24%
14	Denmark	1.59%	1.87%	0.61%
15	Israel	1.59%	1.58%	1.62%
16	Sweden	1.54%	1.70%	1.01%
17	Norway	1.36%	1.52%	0.81%
18	Slovenia	1.23%	0.53%	3.64%
19	Ireland	1.04%	0.94%	1.41%
20	Austria	0.45%	0.53%	0.20%
21	Poland	0.32%	0.35%	0.20%
22	Switzerland	0.32%	0.35%	0.20%
23	Latvia	0.23%	0.18%	0.40%
24	Romania	0.23%	0.18%	0.40%
25	Cyprus	0.05%	0.06%	0.00%
26	Czech Republic (Czechia)	0.05%	0.00%	0.20%
27	Estonia	0.05%	0.06%	0.00%
28	Luxembourg	0.05%	0.00%	0.20%
29	Malta	0.05%	0.06%	0.00%
30	North Macedonia	0.05%	0.06%	0.00%
31	Turkey	0.05%	0.00%	0.20%

Table 46. *Country of residence.*

TYPE OF LUNG CANCER	All participants (n=2,176)	People with LC (n=1,686)	Caregivers (n=490)
Non-small cell lung cancer (adenocarcinoma)	70.36%	75.09%	54.08%
I don´t know	7.26%	6.47%	10.00%
Small cell lung cancer	6.43%	4.51%	13.06%
Non-small cell lung cancer (squamous)	4.55%	3.44%	8.37%
Non-small cell lung cancer (other subtype)	4.00%	3.50%	5.71%
Another type of lung cancer	3.31%	3.14%	3.88%
Non-small cell lung cancer (large cell carcinoma)	2.02%	1.72%	3.06%
Non-small cell lung cancer (adenosquamous carcinoma)	1.52%	1.60%	1.22%
Non-small cell lung cancer (sarcomatoid carcinoma)	0.55%	0.53%	0.61%

Table 47. *Type of lung cancer.*

STAGE AT DIAGNOSIS	All participants (n=2,176)	People with LC (n=1,686)	Caregivers (n=490)
Localized (thorax): Stage I-II	25.55%	28.23%	16.33%
Locally advanced: Stage III	16.68%	16.25%	18.16%
Advanced: Stage IV	56.20%	53.86%	64.29%
I don´t know	1.56%	1.66%	1.22%

Table 48. *Stage at diagnosis.*

TUMOUR BIOMARKER	All participants (n=2,160)	People with LC (n=1,671)	Caregivers (n=489)
EGFR	23.47%	25.97%	14.93%
ALK	21.76%	22.50%	19.22%
I don´t know	21.11%	18.79%	29.04%
No, the tumour is not positive for any biomarkers	10.60%	10.83%	9.82%
The tumour has not been tested for biomarkers	8.61%	7.00%	14.11%
PD-L1	7.04%	7.24%	6.34%
KRAS	6.02%	6.64%	3.89%
ROS1	3.80%	3.89%	3.48%
Still in the process of biomarker testing	1.62%	1.38%	2.45%
BRAF	1.53%	1.56%	1.43%
MET	1.44%	1.44%	1.43%
HER2	1.30%	1.26%	1.43%
RET	1.30%	1.50%	0.61%
FGFR1	0.28%	0.18%	0.61%
CTLA-4	0.23%	0.12%	0.61%
NRAS	0.23%	0.24%	0.20%
NTRK	0.19%	0.18%	0.20%
NRG1	0.05%	0.00%	0.20%
Other	2.82%	2.81%	2.86%

Table 49. *Tumour biomarker.*

TIME SINCE DIAGNOSIS	All participants (n=2,194)	People with LC (n=1,701)	Caregivers (n=493)
Less than one year	24.52%	21.93%	33.47%
1 to 3 years	36.19%	35.51%	38.54%
Between 3 and 5 years	19.05%	20.58%	13.79%
5 years or more	20.24%	21.99%	14.20%

Table 50. *Time since diagnosis.*

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Lung Cancer Europe

Many Faces, One Voice

Lung Cancer Europe (LuCE) is the voice of
Europeans impacted by or at risk of lung cancer

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