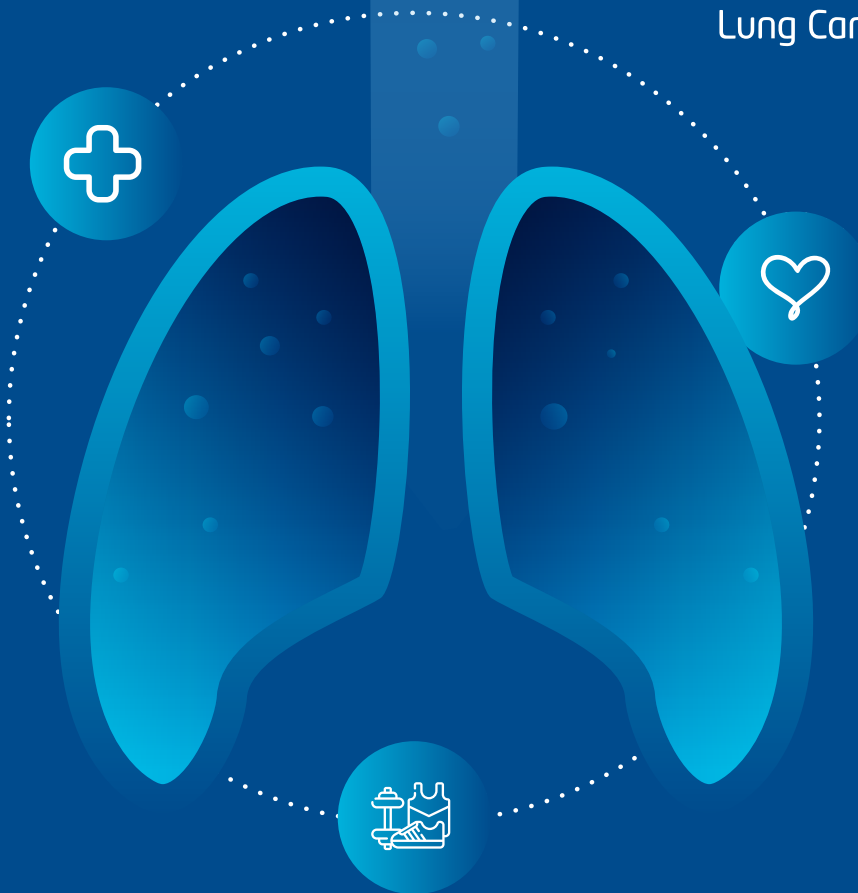




Lung Cancer Europe



Lung Cancer Europe

6th LuCE Report on lung cancer

November 2021

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





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6th
LuCE REPORT ON
LUNG CANCER

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

November 2021



Lung Cancer Europe

WELCOME TO THE 6th EDITION OF THE LuCE REPORT

This is an annual initiative led by lung cancer patient organisations, across Europe with the purpose of raising awareness relating to the main challenges faced by people impacted by this disease.

Life goes on after a lung cancer diagnosis and this report tries to capture insights of people impacted by this disease.

Many faces, one voice.

*The report highlights the
importance of person-centred
pathways from diagnosis to
treatment and survivorship.*



Most people do not know a lot about lung cancer prior to getting diagnosed. Well, other than it doesn't have a good prognosis for many people. However, lung cancer continues to be one of the most common cancers worldwide. It was estimated, that in 2020 about 320,000 people residing in EU countries were expected to be diagnosed with lung cancer. Furthermore, it is expected to continue to be the leading cause of cancer-related deaths with over 257,000 yearly deaths across the EU. (JRC, 2020)

The global COVID-19 pandemic has had tremendous effect on the quality of life of people living with lung cancer and their caregivers in many ways. Avoiding the risk of being infected by the virus, may have forced many to stay isolated, not meet with friends or postpone visits to healthcare clinics. Additionally, many have experienced challenges in accessing mental health and other allied health care supports. However, these challenges have been faced by many living with lung cancer irrespective of the COVID-19 pandemic.

This year, Lung Cancer Europe (LuCE) conducted a study focusing on the experiences and challenges of people with lung cancer and their caregivers, in their everyday life, their lifestyle and future plans in their "new normal".

The report gives an insight into how people with lung cancer manage the symptoms and side effects of the disease and its treatments. It also describes the types of support caregivers provide, from practical needs (like driving to doctor appointments and handling health insurance issues) to providing emotional encouragement. The report also sheds light on the caregivers' role, the high level of subjective stress and need for emotional support.

The report highlights the wide range of healthcare needs, the importance of multidisciplinary and person-centred pathways from diagnosis to treatment and survivorship.

LuCE continues to work actively to raise public awareness about lung cancer; early detections of symptoms, treatment options and the challenges faced by people impacted by this disease across Europe.



Marjo Forsbloom

Patient advocate
Board Member of Lung Cancer Europe (LuCE)

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1. About this report

1.1. DESCRIPTION AND OBJECTIVES

Lung Cancer Europe (LuCE) is an independent non-profit organisation, which aims to advocate European policies that lead to improvements in early detection, treatment and care.

As an active member of the lung cancer community, we are aware of the significant impacts in the daily quality of life (QoL) brought about by the diagnosis of this disease. The physical, emotional and social repercussions of lung cancer contribute to the complexity of living with this disease. This burden is higher in lung cancer than some other cancer types¹, not only profoundly affecting those diagnosed, but also affecting caregivers and families.

With improved outcomes, concerns regarding QoL issues have gained attention among the scientific and medical community. In this context, it is important to capture the patients' perceptions of QoL concerns, and not only the clinician's perspective, as previous studies have shown a low correlation between the two².

With lung cancer, the majority of people are diagnosed with advanced stage disease. As a consequence, supportive care is essential to ensure that appropriate management of symptoms and side effects are provided in order to maximise QoL by minimising functional issues. In this context, it is paramount that needs are clearly recognised and understood. Care for people living with lung cancer must be organised in pathways that cover the patients' and caregivers' needs from their own point of view¹.

This report titled 'Experiences and quality of life of people impacted by lung cancer in Europe' is a **descriptive research analysis that explores the experiences of people impacted by lung cancer in Europe along their disease journey**. The report tries to identify the

impact of the disease on their physical functioning, well-being and daily life.

This research has been designed to examine the personal experiences of those affected by lung cancer, and to increase knowledge and awareness of how lives are impacted throughout the evolution of the disease. This report highlights the importance of multidisciplinary and person-centred pathways along the disease journey.

Our 2020 LuCE Report concentrated on the ‘Psychological and social impact of lung cancer’ and was focused on the major emotional and social issues experienced by people impacted by lung cancer in Europe. Our current report follows on from that research, with our findings in 2021 identifying a broad spectrum of healthcare needs among people impacted by lung cancer.

RESEARCH OBJECTIVES:

- To explore the experiences of people impacted by lung cancer in Europe through their disease journey and how this affects their daily life and physical functioning.
- To provide those living with lung cancer and their caregivers the opportunity to share their opinions and insights regarding the healthcare received and their personal involvement in treatment and care decision making.
- To explore perceived QoL and the level of impact of the disease on participants daily lives.

1.2. METHODOLOGY

Literature review

A comprehensive literature review was conducted in January-March 2021, using the electronic database Pubmed. The search focused mainly on QoL, symptoms, side effects and physical functioning of people impacted by lung cancer. Publications were limited to the English language.

Previous findings reported in the literature were used to aid in the design of an online survey aimed at those impacted by lung cancer (people with lung cancer and caregivers) and a set of questions for qualitative interviews. References can be found at the end of this report.

Qualitative interviews

Sixteen interviews were conducted with people impacted by lung cancer between May - July 2021. Inclusion criteria included anyone living with a diagnosis of lung cancer or caring for someone with lung cancer, residing in Europe and above 18 years of age.

The purpose of these interviews was to understand the **interviewee's perceptions, experiences and insights in relation to their life experiences** following a diagnosis of lung cancer, while identifying areas for improvement in the health care system (footnote^a).

Interviews lasted between 30 and 45 minutes and were conducted over the phone or by telematic means. If the interviewee did not speak English, the interview was carried out through a questionnaire written in the interviewee's language. Participation in the interview was confidential.

The final sample (n=16) consisted of eight people with lung cancer (four men and four women) and eight people who have cared for someone with this disease (four men and four women). People interviewed were from ten European countries: Finland (1), Greece (2), Ireland (1), Italy (1), Norway (1), Poland (2), Romania (2), Slovenia (1), Spain (4) and The United Kingdom (1).

- People with lung cancer: Interviewees ranged in age from 45 to 72. The mean age was 57.5. Seven were diagnosed with non-small cell lung cancer (NSCLC) (6 at Stage IV; 1 at Stage II) and the diagnosis of one respondent was unknown. Four were in active treatment and four were not in active treatment.

^a The questionnaire can be accessed at: www.lungcancereurope.eu

- Caregivers: Interviewees ranged in age from 32 to 72. The mean age was 50.5. Five were primary caregivers. Regarding their relationship to the person with lung cancer, four of them were the significant other, two of them were their son/daughter, and two of them were another relative. Four participants cared for people not receiving active treatment, two in active treatment and two had cared for someone who had passed away.



If you see this box in the text, it includes a transcribed quote from these qualitative interviews.

Online survey

a) Survey design

A survey was drafted in conjunction with Fundación MÁS QUE IDEAS (Spain), and reviewed by a committee of five patient advocates (members of the LuCE Working Group). Data was collected through a **self-filled online survey** via the “SurveyMonkey®” platform. **The survey was open to people impacted by lung cancer** (people with lung cancer and caregivers) and its **objective was to explore their experiences with lung cancer**. It was confidential and it did not include questions relating to identifiable personal information.

The first question acted as a filter to determine if the respondent was (1) a person with lung cancer (followed by 45 questions); (2) a person who cared for someone with lung cancer (followed by 43 questions); (3) another person (excluded from the survey when neither a person with lung cancer or someone who cared for a person diagnosed with lung cancer).

Most questions did not require a mandatory answer, so participants could decide which questions they wanted to respond to.

This survey was **translated into 15 languages**: Danish, Dutch, English, Finnish, French, German, Greek, Hebrew, Hungarian, Italian, Latvian, Polish, Romanian, Slovenian and Spanish (footnote^b).

^b The English version of the questionnaire can be accessed at the following link: www.lungcancereurope.eu

b) Survey limitations

While this technique is widely used, it does give rise to certain limitations, such as difficulties in reaching certain types of participants. As a consequence, there may be an underrepresentation of the elderly in our research. A total of 26.8% of participants were over 65 years, although this age group represents the majority of people diagnosed with lung cancer. This age cohort have increased risk of co-morbidities³ which can impact their experience living with the disease. This bias should be considered when analysing this report.

There is also a female over-representation in the survey participants that should be considered when interpreting the data: 74.8% of people with lung cancer and 80.7% of caregivers were women.

Another limitation concerns people receiving end-of-life care. Only 1.8% of respondents were receiving this type of care, thus data gathered from this group is unlikely to address the specific needs of those experiencing end-of-life care.

c) Survey dissemination

The survey was **active from May 20th - July 1st, 2021**. It was disseminated through the communication channels of LuCE and LuCE members, including websites, direct email and social media channels. The main routes of dissemination were patient associations, non-governmental organisations (NGOs) and patient advocates.

d) Data analysis

A quality control check of the data was performed to identify and remove invalid answers (Refer to 'General characteristics'). Data generated from the different language versions were integrated together using SurveyMonkey® analytic tools.

Open questions were translated into English, aggregated and standardised into a single curated data set.

Finally, data from qualitative interviews, online surveys and the literature review, were combined to create a draft of this report, which was reviewed by the LuCE Board, the LuCE Working Group and Fundación MÁS QUE IDEAS. A finalised version of the report was then prepared.

2. Summary of results

RESULTS: People diagnosed with lung cancer

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

These limitations affected their ability to perform basic (feeding, dressing, etc.) and instrumental activities (shopping, housework, etc.). One-third experienced significant changes in their ability to shop, climb stairs and walk for longer than 15 minutes.

Thus, 48.0% of respondents acknowledged needing **assistance to perform at least one daily activity** (sometimes-often-always). This requirement was especially challenging for 16.2% of participants, who needed help frequently.

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

Although the side effects of lung cancer and its treatment are sometimes severe, 66.2% of participants stated that they were feeling good, and 66.0% said they were able to meet the needs of their families. However, there is still a significant 26.9% of participants that felt overwhelmed by the side effects they experienced.



Most participants acknowledged having a good **QoL** at the time of completing the survey with 69.4% selecting positive ratings of 5-7 (where 1 reflected very poor QoL and 7 reflected excellent QoL). However, they reported some **factors that negatively impacted their QoL**:

- 77.0% experienced problems with memory, concentration or their thought process, which they felt interfered with their daily life.

- 55.1% reduced their physical activity level since diagnosis. This was mainly due to fatigue and breathlessness. The three main barriers for physical exercise were related to fatigue (65.8%), breathlessness/cough (51.8%) and pain (31.3%).
- 49.5% reported eating difficulties, highlighting dry mouth (21.3%), taste or smell changes (20.4%) and appetite loss (19.7%).
- 78.3% reported sleeping problems mainly due to worries and intrusive thoughts (60.5%), nocturia (28.4%) and pain/discomfort (27.9%).
- 24.9% reported a severe impact on sexual relationships. Fatigue was reported as the main reason for the deterioration of their sexual life (37.1%), followed by emotional issues (36.8%) and body changes (30.1%).

Most participants were satisfied with the **support they received**. However, it is worrying that 35.4% reported dissatisfaction, and that 52.8% did not feel equipped to self-manage their symptoms and side effects. In addition, only 59.7% of participants felt they received all the information they required by *'quite a bit / very much'*.

On the other hand, less than half of respondents (45.7%) always reported symptoms and side effects to their healthcare providers. People with a lower education level were identified as reporting issues far less frequently than those with a higher education level.

Our survey identified some **challenges in patient involvement** in decision making, with 1 in 4 having little to no involvement in their healthcare decisions, and 1 out of 5 felt that their opinion was never or rarely considered. However, the majority of participants showed **satisfaction regarding the healthcare** they received - 68.1% reported rapid access to specialists and 70.9% felt that their healthcare team were able to coordinate their disease journey. Thus, most participants showed high satisfaction regarding their communication with their healthcare team.

However, our report findings show an urgent need to improve **communication regarding end-of-life care**. Only 8.8% had fully discussed their preferences regarding end-of-life-care decisions with their healthcare team. It is particularly significant that 1 out of 3 participants (32.2%) had not discussed end-of-life care, even though they would have liked to.

RESULTS: People caring for someone with lung cancer

A total of 88.6% of participants acknowledged some **limitations in daily life** related to caregiving. These limitations were especially high for 1 out of 4 participants (27.3%). Main reasons for this were their own emotional concerns (63.1%), treatment requirements (54.1%) and caregiving responsibilities (49.1%).

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

The majority of participants (60.9%) were satisfied with the care and support they provide. However, they experienced some difficulties in **balancing caregiving with other responsibilities and their own care**:

- 46.2% reported that they did not feel that they had time for themselves.
- 30.7% stated that they had lost their personal privacy.
- 82.3% reported some physical health deterioration since they started caregiving. The two physical problems that most impacted participants were sleep disturbances (94.7%) and fatigue (91.1%), with 64.4% stating that they often felt physically exhausted.
- 51.8% stated that they did not self-care at all or just a little bit.
- 53.7% had reduced their physical activity, primarily due to their emotional situation (59.5%) and fatigue (53.2%).
- 46.6% reported a negative impact on nutrition because their eating patterns had changed due to stress (67.6%) and that their nutrition had become a secondary concern (59.8%).
- 36.9% acknowledged that they had not attended all their own medical appointments.



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

Few (11.5%) said they received support from healthcare professionals in delivering the best care possible to their loved one. Thus, more than half (56.2%) reported that they did not receive any support to maintain and improve their own health and QoL. A total of 84.4% identified at least one information or support need. The most frequent were psychological counselling (51.9%), help to deal with side effects (41.6%), and medical information (41.6%).

There are two main reasons that may explain the lack of support for caregivers: Firstly, healthcare professionals may be focused primarily on the physical needs of the patient, and secondly caregivers often avoid asking for help. Half of caregivers (49.8%) recognised that they rarely or never asked for help. The reason most frequently reported was that they did not want to worry their loved one about their own needs (53.0%).

Our research shows the active **role of caregivers in the treatment decision** process. Eight out of 10 were directly involved in treatment decisions and 32.2% stated they were the primary decision-maker. Therefore, communication between people living with lung cancer, caregivers and the care team are crucial. However, 44.3% of caregivers guarded medical information to protect their loved one and 77.3% acknowledged to have hidden their feelings and concerns about the disease.

Support for people experiencing **end-of-life care is essential**. For those whose loved one had passed away (n=71), 37.2% valued support received during the last days of life in a positive way, while 34.3% valued it negatively. Main difficulties identified were patient symptom management (77.9%), how to best offer emotional support (76.5%), how to offer best care (76.5%) and patient comfort and dignity (73.5%). It is worrying that 40.6% were not satisfied with the discussions they had with their loved one about end-of-life decisions. Although 68.1% acknowledged to having shared their feelings with their support network, half of those reported that this level of sharing was not enough.

For those still actively caregiving (n=127), 50.0% of participants confirmed that they discussed end of life care with their loved one. However, half considered that they had not discussed it enough, and we identified a further 9.5% who had not talked about end of life, although they would have liked to. A third of respondents (33.4%) said that they shared their feelings with their support network. There is a clear need to promote these types of conversations as 34.2% would like to talk about their feelings to a greater extent.

3. RESULTS: Participants characteristics

The total number of respondents numbered 867. However, 67 were disqualified because 65 respondents were neither people with lung cancer nor caregivers and 2 did not reside in the WHO European region.

The final sample size totaled 800 participants: 515 people with lung cancer (64.4%) and 285 caregivers (35.6%). Some participants did not complete the entire survey. Therefore, the number of valid responses per question varies.

All demographic and general lung cancer information are presented in Annex 1. Below is a summary of main participant characteristics.

People with lung cancer: characteristics

- The majority were women (74.8%) between 55-64 years of age (40.2%). Most respondents came from The Netherlands (17.7%), France (11.1%), Spain (11.1%) and Italy (10.3%). Regarding education, 41.1% had attained upper secondary education and 47.9% tertiary education.
- 75.6% were diagnosed with 'non-small cell lung cancer – adenocarcinoma' and 68.2% confirmed that their tumor was positive for a molecular marker, mainly ALK (21.6%) or EGFR (16.5%).
- 59.9% had Stage IV disease and the main metastatic locations were lymph nodes (38.8%), bones (28.6%) and brain (24.1%).
- The most frequent treatment received by participants was chemotherapy (55.1%), followed by radiotherapy (46.9%), targeted therapy (42.0%),

immunotherapy (34.8%) and surgery (32.1%). 67.5% of participants were on active treatment at the time of completing this survey.

Caregivers: characteristics

- The majority were women (80.7%), between 35-40 (30.2%) years of age. The majority of respondents came from Greece (22.8%), The Netherlands (19.3%) and Spain (13.3%). 34.5% had attained upper secondary education and 57.4% tertiary education.
- 42.8% of respondents were the partner and 41.8% the son/daughter of the person diagnosed with lung cancer.
- 85.6% of participants were the primary caregiver with 34.4% stating that they were the only caregiver.
- Around half of caregivers (51.6%) stated that their loved one had Stage IV disease.

4. RESULTS: People diagnosed with lung cancer

4.1. DAILY LIFE AND FUNCTIONING.

People diagnosed with lung cancer tend to have a higher prevalence of comorbidities, often more complex and severe, than people living with other types of cancer⁴. People often experience limitations with their functional state and social activity, factors that greatly affect their QoL⁵.

According to our survey, since diagnosis, **91.2% of respondents experienced some limitation in their daily activities**. The level of impact was contingent on a number of factors. Several were directly related to lung cancer, such as the type of disease, the treatment received, and their subjective experience with side effects and symptoms. However, previous research has shown how treatment and personal care factors such as medical follow-up or personal resources and experiences are also important⁶. Our data shows that **1 out of 4 people with lung cancer have experienced severe limitations in their daily activities (quite a bit / very much)** (Fig.1).

Have you experienced limitations in daily activities related to lung cancer and treatments?

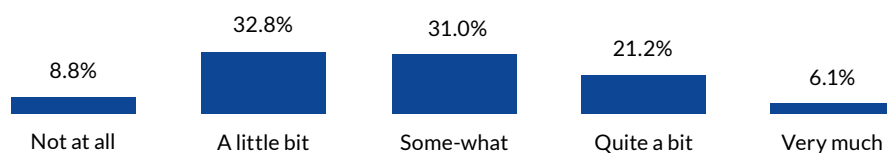


FIGURE 1. Limitations in daily activities (n=509).

70.9% expressed limitations to their daily activity mainly due to severe fatigue. Fatigue was the most prevalent and severe side effect for people who participated in this survey (Fig. 2).

Other limitations reported included breathlessness (42.8%), emotional issues (39.4%), treatment requirements (35.6%) and pain (32.1%) (Fig. 2).

“Learning to deal with limitations and having to adapt my routines to them has been quite difficult”.

“It’s been difficult for me to meet up with friends, cause when they are going out when I just want to go to bed”.

“I went from being an independent professional to a patient who needed back surgery and a lot of treatments for the cancer”.

In case you have ever experienced limitations in daily activities related to lung cancer and treatments, what have been the reasons?

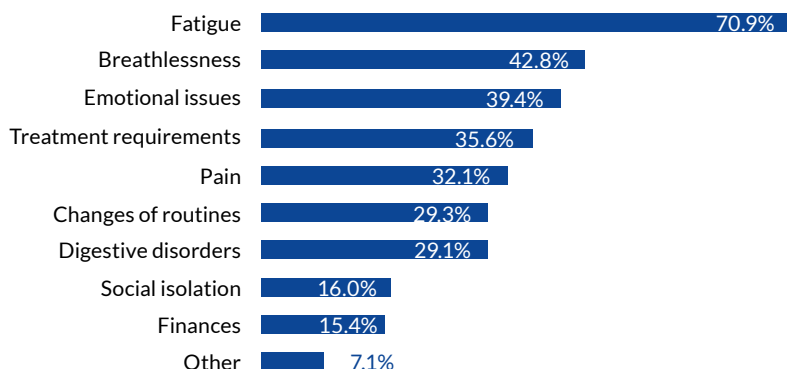


FIGURE 2. Reasons of limitations in daily activities (n=495).

Those receiving active treatment reported a higher incidence of daily activity limitations compared to those not on treatment (as given in brackets). This was due to digestive disorders (31.0% vs. 20.0%) and treatment requirements (37.5% vs. 28.2%). On the other hand, breathlessness was more frequently reported by people who have completed any type of treatment (57.3% vs. 34.8%).

One of the top factors that influenced QoL was the **ability to perform basic activities of daily living** (feeding, dressing, toileting, etc.) and **instrumental activities** of daily living (shopping, housework, cooking, etc.). Irrespective of treatment, participants experienced more limitations in instrumental compared to basic activities.

Table 1 shows how people with lung cancer experienced changes in many different basic and instrumental activities. More than half of participants reported difficulties related to shopping, climbing stairs, walking more than 15 minutes, housework and feeding.

Compared to your life before diagnosis, have you ever experienced changes in your ability to do any of the following activities?

| | Not at all | A little bit | Some-what | Quite a bit | Very much |
|--------------------------------|------------|--------------|-----------|-------------|-----------|
| Shopping: heavy shopping bag | 22.7% | 26.4% | 15.1% | 18.5% | 17.3% |
| Stair climbing | 18.8% | 30.9% | 17.4% | 17.2% | 15.8% |
| Walking (more than 15 minutes) | 31.8% | 22.5% | 16.6% | 14.4% | 14.8% |
| Housework | 21.4% | 30.6% | 25.2% | 15.0% | 7.8% |
| Transportation / Transfers | 38.9% | 26.9% | 15.4% | 10.2% | 8.6% |
| Feeding | 43.0% | 25.1% | 16.3% | 9.0% | 6.6% |
| Walking (less than 15 minutes) | 51.1% | 22.2% | 12.2% | 7.2% | 7.2% |
| Cooking and food preparation | 50.4% | 23.8% | 14.3% | 7.3% | 4.2% |
| Handle finances | 58.6% | 17.4% | 12.8% | 6.4% | 4.8% |
| Dressing | 60.8% | 23.1% | 10.0% | 4.2% | 1.8% |
| Personal hygiene / Toileting | 67.9% | 19.0% | 7.6% | 3.4% | 2.0% |

TABLE 1. Changes in ability to do daily activities (n=506).

Two factors that could contribute to an overall decline in the general ability to perform daily tasks are the age of the person and the severity of their disease⁷. Results from this report, however, did not show a clear association. As would be expected, **people with localised lung cancer (n=114) experienced less impairments in their daily activities compared to those with advanced disease (n=381)** (except 'stair climbing'). However, people with locally advanced disease (Stage III) (n=75) reported a higher impact than those with Stage IV disease (n=306) in all items, except 'personal hygiene', 'transportation' and 'handling finances'. On the other hand, our data did not show evidence of significant differences in the ability to perform daily activities depending on the age of the participants.

Since neither age nor severity of the disease predict limitations, the **assessment of functional status is critical** to assist the clinician to recognise changes at an early stage that may signify a need either for additional resources or for a medical work-up⁸⁻⁹. These resources should be available to help people improve their independence and functional performance. For people who needed daily assistance, this is a clear priority.

In this sense, **48.0% of respondents acknowledged needing assistance to perform at least one daily activity** (sometimes-often-always). This requirement was especially challenging for 16.2%, who needed help frequently (Fig. 3). Difficulty with or requiring assistance in at least one activity has been previously associated with poorer QoL, and in older adults is a factor predictive of mortality¹⁰.

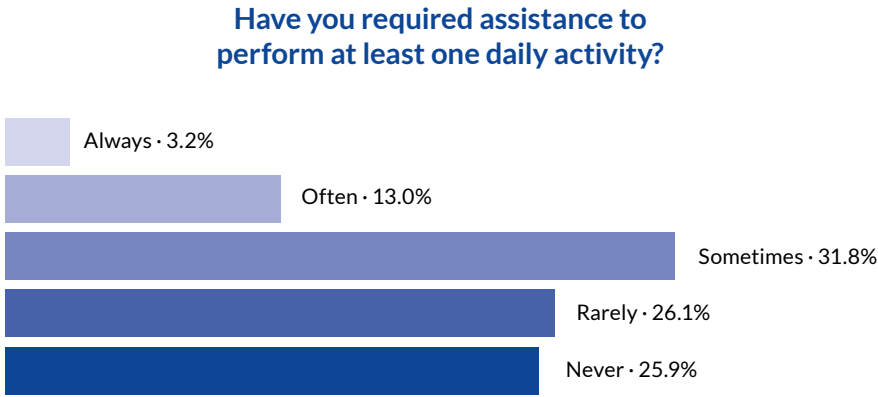


FIGURE 3. Assistance to perform daily activities (n=506).

This data is consistent with other studies and should encourage healthcare systems to facilitate access to **rehabilitation services focused on functional independence**. Improving occupational therapy services for people with lung cancer seems an essential step in reducing the burden of this disease in different spheres of life¹⁰.

The burden of symptoms, exercise intolerance and physical deconditioning are among the most prevalent factors affecting the daily lives of those living with lung cancer¹⁰. These factors have the potential to impact virtually all aspects of life, including their ability to work or make plans for their future. This has an impact on finances and independence, which ultimately may lead to changes in lifestyle and family relationships. According to our results, **the greatest impacts reported by participants surveyed was on future plans, followed by work and lifestyle** (Fig. 4).

To what degree have the following areas of your life been affected since diagnosis?

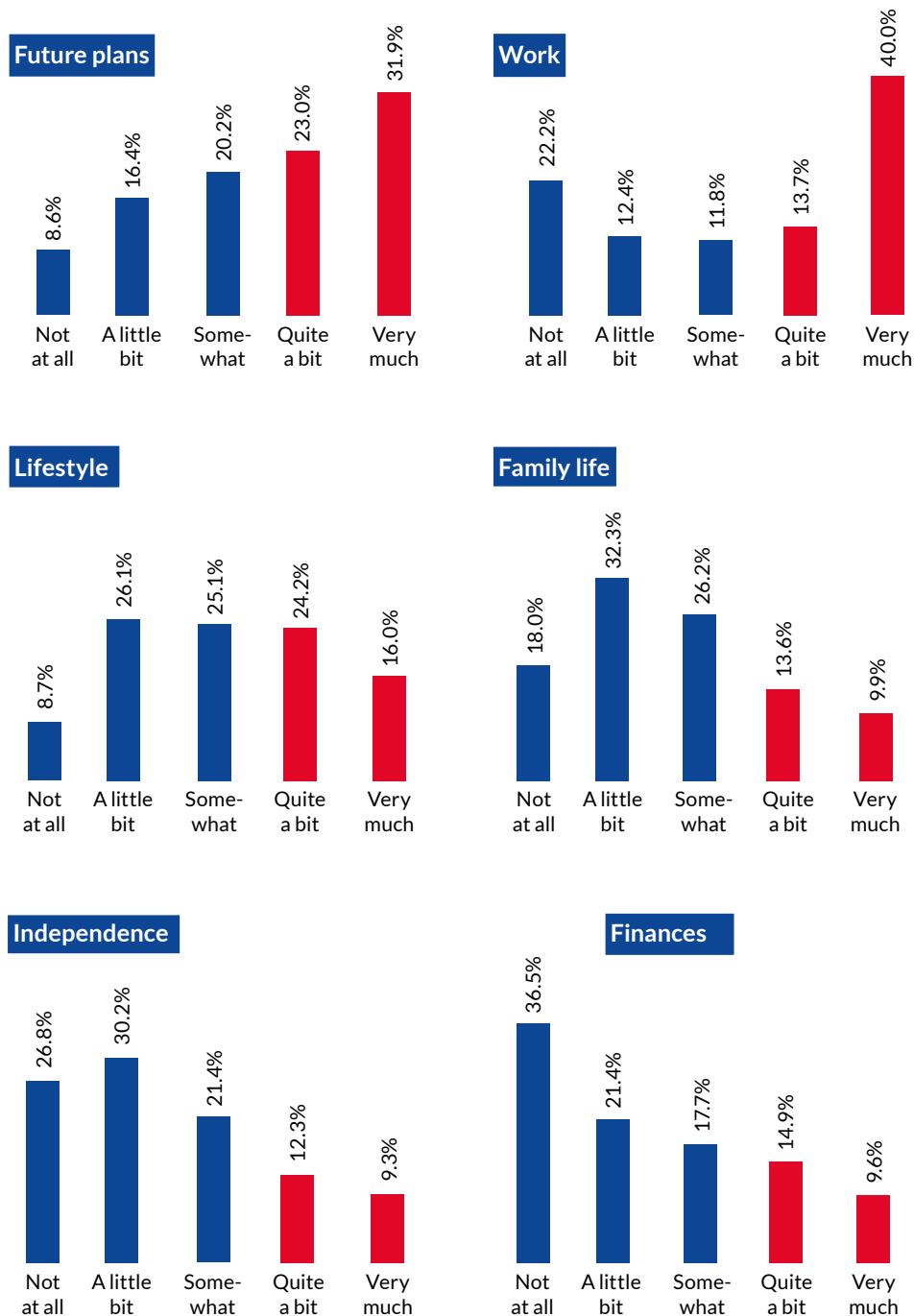


FIGURE 4. Areas of life affected since diagnosis (n=505).

The top three reported impacts since diagnosis were:

- **Future plans:** 54.9% reported a high impact (quite a bit/very much). There was a significant difference between people with localised and people with advanced disease. While 21.3% of those with localised reported a high impact, this proportion increased to 37.3% in people with Stage IV disease. Moreover, people on active treatment reported much higher impact than those who had completed treatment (footnote^c).
- **Work:** 53.7% reported a high impact. This was reported by 46.2% of people with Stage IV, which fell to 21.4% in those with Stage I-II. As in the previous case, people on active treatment reported a higher impact than those who had completed treatment (footnote^d).
- **Lifestyle:** 40.2% reported a high impact. There were also significant differences in the report of high impact on lifestyle between people with advanced disease (42.2%) and localised disease (29.9%).

All those with lung cancer (n=8) who were interviewed for this report talked about how the experience of living with lung cancer had greatly changed their daily lives and routines. Four of them pointed out that their main challenge was accepting their diagnosis and living with the uncertainty of a bad prognosis. Other challenges reported by four people was living with the limitations caused by side effects and symptoms.

All interviewees mentioned some social consequences of living with lung cancer, mostly related to changes on social life, work and finances.

“I went from being busy with my job to suddenly doing nothing. I wasn’t healthy enough to participate in any sports or even to take care of my house.”

“I was already retired so the biggest change I experienced was in my social life. I was always tired when going out to meet people.”

“I had to adapt to a new economic situation. I felt uncomfortable with it.”

“I have very few friends left. I don’t have the time or energy as I used to have. I also don’t have the same job as before.”

^c FUTURE PLANS. On active treatment: No impact (5.9%); High impact (56.5%) / Completed treatment: No impact (15.2%); High impact (42.9%).

^d WORK. On active treatment: No impact (19.4%); High impact (55.2%) / Completed treatment: No impact (28.8%); High impact (46.8%).

4.2. LIVING WITH SIDE EFFECTS AND SYMPTOMS.

Lung cancer is associated with higher disease burden, more physical hardships, and greater symptom distress than other cancer types¹. The health of people with this disease declines both as a consequence of the illness itself, and because of side effects from the treatments they receive¹¹.

The majority of people (approx. 80%) are diagnosed with advanced stage disease. Frequently, before diagnosis they experience symptoms such as a persistent cough, coughing up mucous and blood, breathlessness, chest infections, tiredness, and weight loss, among others¹. Some people may experience symptoms for a long time but normalise them (wait and see) as they may be non-specific and overlap with other conditions and diseases¹².

The most common symptoms and side effects reported by participants were fatigue (92.8%), sleep disturbances (78.3%), weight changes (76.6%), breathing difficulties (75.7%) and digestive disorders (75.0%).

When we examined the level of severity of these side effects on well-being, we found that **fatigue** (45.3%), **weight changes** (31.7%), **sleep disturbances** (29.0%), **digestive disorders** (28.5%) and **sexual issues** (24.9%) were the effects that most impacted participants' QoL by 'quite a bit / very much' (Table 2).

To what extent have these symptoms and side effects impacted your QoL?

| | Not at all | A little bit Some-what | Quite a bit / Very much |
|---|------------|---------------------------|----------------------------|
| Fatigue | 7.2% | 47.5% | 45.3% |
| Sleep disturbances | 21.7% | 49.3% | 29.0% |
| Weight changes | 23.4% | 44.9% | 31.7% |
| Digestive disorders | 25.0% | 46.6% | 28.5% |
| Sexuality issues | 32.2% | 42.8% | 24.9% |
| Breathing difficulties | 24.3% | 55.0% | 20.7% |
| Hair changes | 37.2% | 38.0% | 24.8% |
| Neuropathy | 36.1% | 45.1% | 18.8% |
| Pain | 35.9% | 46.1% | 18.0% |
| Skin alterations | 36.3% | 49.2% | 14.6% |
| Nail issues | 48.0% | 34.1% | 17.9% |
| Eating difficulties | 50.5% | 39.5% | 9.9% |
| Edema | 53.4% | 33.6% | 13.0% |
| Eye itching | 52.1% | 36.3% | 11.7% |
| Sore mouth | 55.4% | 34.4% | 10.3% |
| Coughing/Coughing up blood/Phlegm/Mucous | 54.9% | 36.0% | 9.1% |
| Malnutrition | 69.2% | 23.8% | 7.0% |
| Pulmonary infections / Pneumonitis | 76.3% | 17.1% | 6.7% |
| Fertility issues | 87.7% | 6.8% | 5.5% |

TABLE 2. Symptoms and side effects (n=489).

- **Fatigue** is one of the most prevalent and distressing symptoms experienced by people living with cancer, during and after therapy¹³. According to our research, more women reported fatigue (footnote^e). Fatigue continues to be underreported. Cancer-related fatigue is more severe and distressing, and less likely to be relieved by resting, than the fatigue experienced by those who do not have cancer¹⁴. It is rarely described as an isolated symptom and is often associated with sleep disorders¹⁵.



“My physical condition has definitely deteriorated. I don’t have as much energy as before. I had to considerably limit my physical activity”.



- **Sleep disturbance** is a prominent concern for people with lung cancer. It has a detrimental effect on health outcome and causes a decline in individual functional status. One-third of participants stated that sleep dysfunction highly impacted their QoL. Sleep quality in people diagnosed with lung cancer has been identified as the poorest, compared to other cancers and non-cancer control populations. Among people with lung cancer, it is often reported as one of the four most prevalent symptoms¹⁶. The most frequent disorders are insomnia, hypersomnia and circadian rhythm alterations¹⁷.

^e Fatigue: Very much impact (87.0% women; 13.0% men) / Not impact (69.7%; 30.3%)



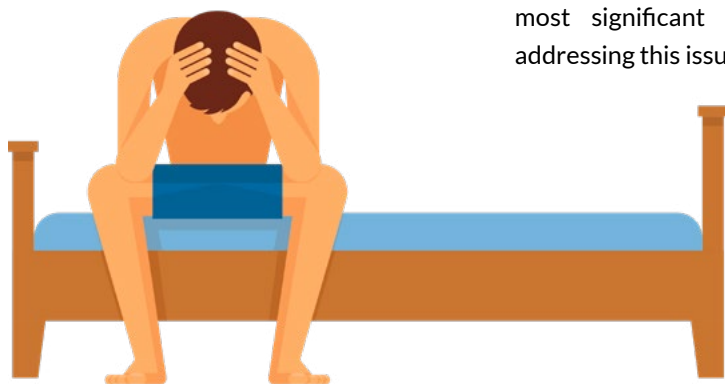
- **Weight changes.** Tumor status and side effects are major determinants of weight changes. Weight loss has been the primary body weight consideration in NSCLC clinical trials¹⁸. 76.6% of survey participants experienced changes in weight, a factor that highly affected their well-being in 31.7% of participants. Weight loss is associated with reduced physical function and reduced tolerance to anticancer therapy and survival¹⁹.

- **Digestive disorders.** During treatment, eating and drinking issues usually affect the majority of those living with lung cancer²⁰. The most common gastrointestinal difficulties are nausea and diarrhea, which can severely affect individuals' daily life and diet²⁴. Personalised nutritional counselling should include family and the person diagnosed with lung cancer food habits and/or preferences. According to 5th LuCE Report (2020), despite the expressed interest of many individuals to receive dietitian/nutritional support and counselling, only a minority of people can access these services.



- **Sexual issues.** 24.9% reported negative impacts on their sexual lives. The percentage of people severely affected is higher in the younger cohorts: 45.1% of people between 35-44 years old stated that the impact on sexuality deeply affected their QoL, while this percentage fell to 16.7% in participants between 65-74. Negative consequences are

driven by cancer or its treatments and can affect emotional and physical intimacy and sexual intercourse²¹. Despite this considerable impact, studies have found barriers with healthcare providers to tackle this issue. Among them, discomfort with the topic of sexuality, lack of knowledge and resources and prejudices and beliefs about the priorities of people are among the most significant reasons for not addressing this issue²²⁻²³.



Women with lung cancer experienced higher symptom burden than men. Comparing participants by gender, our survey found that women reported a higher impact in all items surveyed, with the exception of fertility issues. Differences were more remarkable in issues pertaining to digestive disorders and hair and nail problems.

The high prevalence of symptoms and treatment-related side effects highlights the need for high-quality palliative care, in order to improve the QoL for those living with lung cancer¹¹. However, according to the 5th LuCE Report (2020), only 9.3% of patients had received palliative care²⁴. Palliative care is an approach that improves the quality of life of patients and their families facing a life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (definition from the World Health Organization). This type of care is especially important in lung cancer, since about 80% of those diagnosed have Stage IIIB or IV at the time of diagnosis.

Asked about what helps with coping with the disease and side effects, all people with lung cancer interviewed for this report agreed on the **importance of receiving support beyond medical and nursing assistance.**

"Family support is critical. I have also counted on patient associations, where I found people to talk to and share my experiences and worries".

"It helps to get some support from other patients, I used a local cancer support center, and they were very helpful for companionship, discussion and psychological support and counselling".



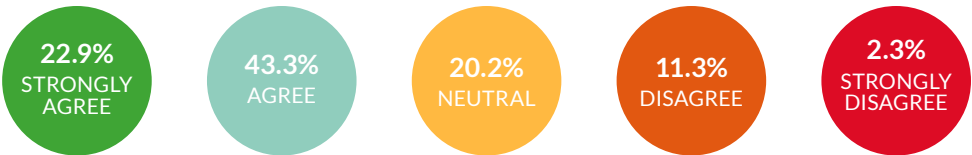
"What has always supported me throughout this whole journey is my faith, my prayers, and the prayers of others".

"Being able to vent my frustrations and worries in support groups has helped me a lot".

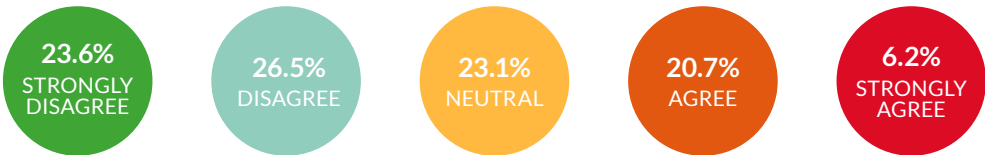
Although the side effects of lung cancer and its treatment are usually severe, 66.2% of participants stated that they were feeling good, and 66.0% said they were able to meet the needs of their families. However, there is still a significant **26.9% of participants that felt overwhelmed by the side effects they experienced** and 16.0% acknowledged that they had not been able to meet their family needs. The severity of the symptoms and side effects is especially high for 12.4% participants, who reported they needed to spend time in bed (Fig. 5).

Do you agree or disagree with the next statements about your experience living with lung cancer symptoms and side effects?

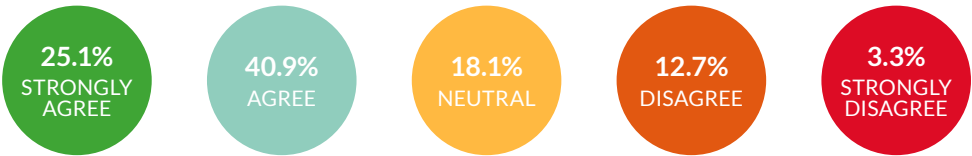
I feel good, despite side effects of treatment.



I have felt overwhelmed by the side effects of treatments.



I am able to meet the needs of my family, despite my physical condition.



I am forced to spend time in bed.

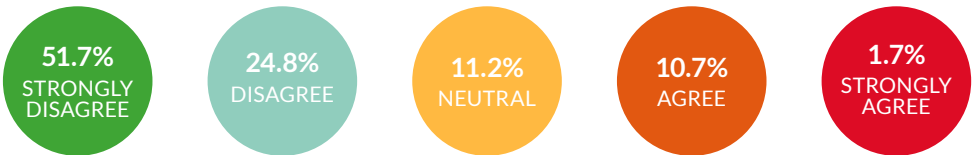


FIGURE 5. Experiences of living with symptoms and side effects (n=488).

Dealing with the strain of having lung cancer and experiencing symptoms and side effects requires appropriate support from healthcare professionals.

Most surveyed (64.6%) were satisfied with the support they received. However, it is remarkable that 35.4% reported dissatisfaction, and that **52.8% did not feel equipped to self-manage their symptoms and side effects** (Fig. 6/7).

How satisfied are you with the support you have received from healthcare professionals to manage your symptoms and side effects?

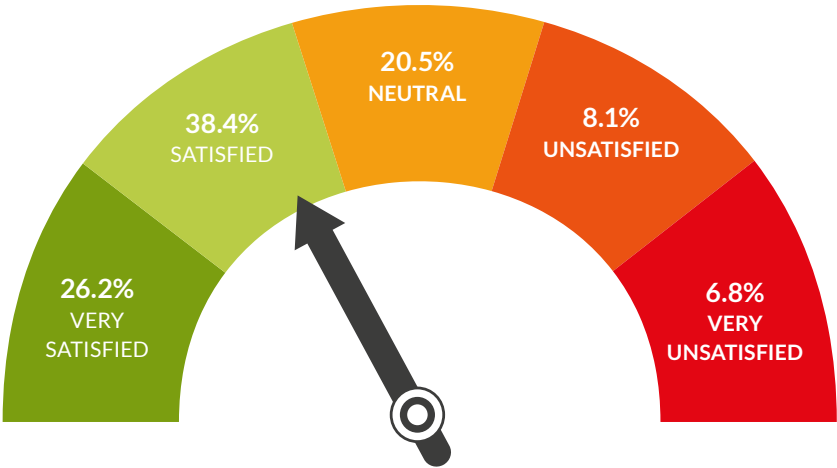


FIGURE 6. Satisfaction with support to manage side effects (n=484).

Have you felt equipped to self-manage symptoms and side effects?

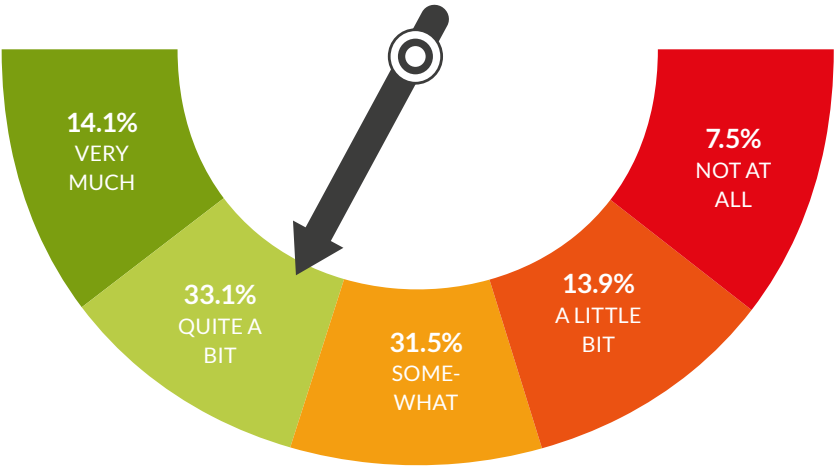


FIGURE 7. Equipped to self-manage side effects (n=483).

One of the main conclusions of the previous LuCE Report (2020) was that management of symptoms and side effects was considered a high unmet need among those living with lung cancer.

People with lung cancer consulted this year (2021) repeated this need again. **1 out of 3 people reported having insufficient support on how to manage side effects** (32.3%). Similar percentages of people also reported the need for **psychological counselling** (31.7%), and the need for more **information about nutrition and exercise** (31.5%) (Fig. 8).

What type of information/support have you missed?

TOP-PRIORITY

33.2%
Side effects
(and how to manage)

31.7%
Psychological
counselling

31.5%
Nutrition
and exercise

30.6%
Medical
information



OTHER IMPORTANT TOPICS

28.1%
Social resources
and rights

25.5%
Patient organisations,
peer support and non-
profit organisations

21.4%
Health system
navigation

FIGURE 8. Information / Support most missed (n=467).

Participants also highlighted the need to improve medical information. 30.6% felt they required more support and information relating to medical issues. Special consideration should be considered for **individuals with primary education only** as their access to **further information may be limited**: 39.5% with a primary education stated their greatest resource need was medical information and support to manage side effects (this is considerably greater than participants with tertiary education: 29.3% and 31.0% missed medical information and support to manage side effects, respectively).

Participants with a lower educational background reported less knowledge about their disease. As Table 3 shows, 15.9% of people with a primary education did not know their type of lung cancer, and 41.6% did not know if their tumour was positive for any marker. Knowledge levels are much lower when compared to people with higher education levels.

| | I do not know my type of lung cancer. | I do not know if my tumour is positive for any marker. | I do not know my current point in the disease trajectory. |
|---------------------|---------------------------------------|--|---|
| Primary education | 15.9% (8 out of 53) | 41.6% (22 out of 53) | 13.2% (7 out of 53) |
| Secondary education | 3.8% (8 out of 208) | 30.3% (63 out of 208) | 5.3% (11 out of 208) |
| Tertiary education | 2.1% (5 out of 244) | 24.1% (58 out of 241) | 4.5% (11 out of 240) |

TABLE 3. Knowledge about the disease per level of education.

Access to medical information is crucial for people with lung cancer. Several studies have shown that people with lung cancer perceive that high-quality information about their treatment was available to them when they required it²⁵. However, our survey indicates that **only 6 out of 10 (59.7%) confirmed having received all the information they required by ‘quite a bit / very much’ (Fig. 9).**

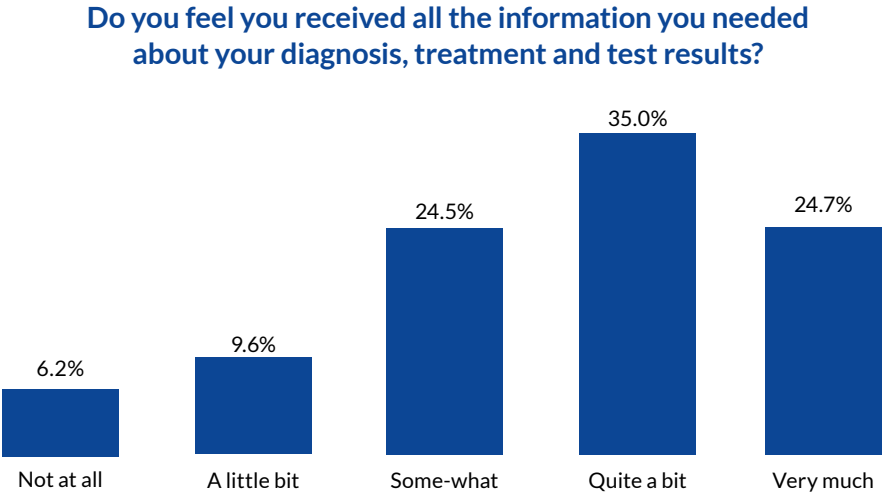


FIGURE 9. Medical information received (n=470).

Of those interviewed, 6 out of 8 felt they were fully informed about their disease and were involved in the decision process. In contrast, one stated that decisions were made by doctors, and another stated that the primary decision-maker was a caregiver.

“I wanted to know about my disease, I asked the doctors to honestly tell me about my prognosis. They told me everything I wanted to know so I felt okay with it”.

“The team I have now informs me about everything and allows me to participate in the decision making”.

“I like to be informed and have some discussion about it but if it's obvious and there is just one way to go, you just have to put your faith in your team and go with it”.

“I would have liked it, but I was told the doctors were thinking about options so - I couldn't influence the treatment and the different choices and different things. I think doctors need to talk to the patient more”.

“My daughter is doing it for me, I don't want to know the details. But I would like her to have full control over my treatment and to know all the possibilities, and to have access to complete medical records”.

People with lung cancer need information and support from healthcare professionals to help with the self-management of side effects. In the same way, healthcare teams need to work with those diagnosed with lung cancer to offer the best care possible. Adequate management of side effects and symptoms requires fluid communication between those with the disease, relatives, and healthcare professionals.

Worryingly, less than half of respondents (45.7%) **acknowledged that they always reported symptoms and side effects** to their healthcare providers. Additionally, **27.3% stated they ‘never / rarely / sometimes’ report issues**. It is important to highlight that **people with a lower education were identified as reporting issues far less frequently** than those with a higher education. More than 20% of respondents with a primary education stated they rarely or never reported issues (Fig. 10).

It is an urgent priority to raise awareness among the community of the importance of reporting symptoms and side effects to their healthcare provider.

Have you shared the symptoms and side effects with your healthcare team and relatives?

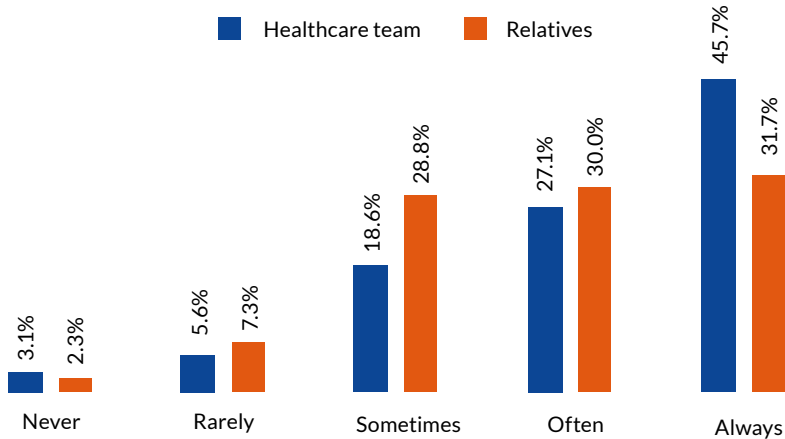


FIGURE 10. Symptoms and side effects reported (n=484).

However, according to our survey, people with lung cancer tend to share their side effects with healthcare professionals to a greater extent than with their relatives. Only 31.7% always shared them with their relatives. In contrast, we observed that **38.4% shared the side effects they experienced with their relatives `never / rarely / sometimes`.**

“I don’t want to spend all day complaining, so I don’t emphasize the symptoms, but when I’m suffering, I let my family and friends know. Especially to the health care team, as I am in a clinical trial, they need to know what is happening to me”.

“I was usually trying to hide the fact that I felt unhappy and guilty for surviving, not the side effects or symptoms from the disease itself”.

4.3. HEALTHCARE AND INVOLVEMENT IN TREATMENT DECISION PROCESS.

a) Access and navigation of the healthcare system.

68.1% of participants stated that they had rapid access to healthcare specialists and 70.9% stated they felt that their healthcare team were able to coordinate their disease journey. Furthermore, 72.9% acknowledged following a well-structured treatment pathway and 71.0% believed they had a clear knowledge of which professional was responsible for each step of the pathway. Approximately 1 in every 10 participants reported a negative experience accessing and navigating healthcare institutions (Fig. 11).



“I’ve always been confident in my team. I’ve felt supported by every single person that attended me, from the secretary to the nurse who did all the tests. It was really pleasant seeing the same faces when I had to go to the hospital”.

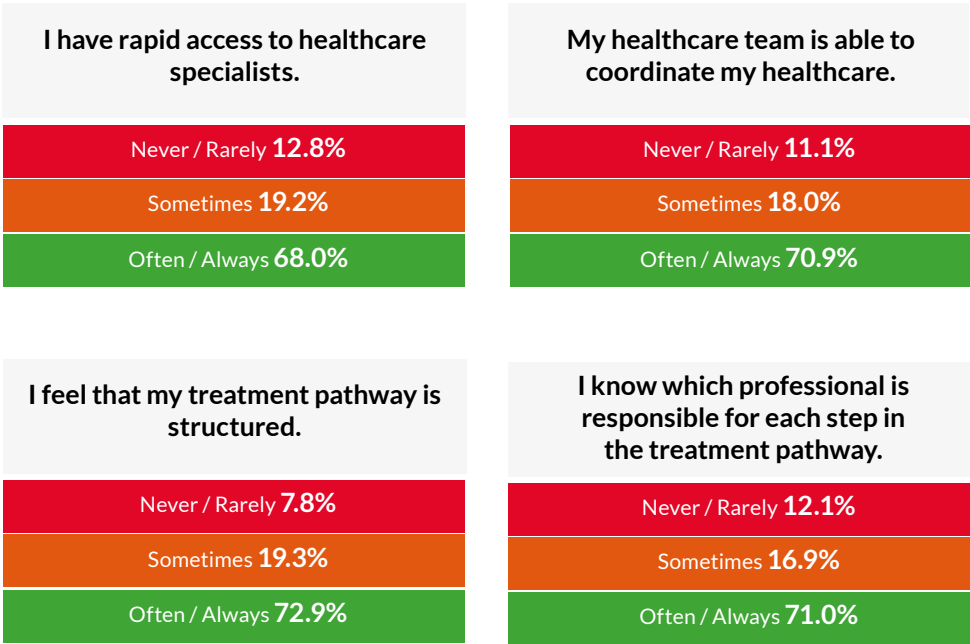


FIGURE 11. Access / navigation of the healthcare system.

b) Communication with the healthcare team.

Overall, participants reported **high satisfaction regarding their communication with their healthcare team**. 76.0% highlighted that the language used was more often easy to understand, and 70.7% felt they could usually express their preferences regarding treatment (Fig. 12). These numbers are similar to those obtained in our 2020 report: 78.1% of people diagnosed with lung cancer thought this communication was positive or very positive²⁴.

However, **communication deficits between people with lung cancer and their healthcare team sometimes do exist**²⁶. We found a significant proportion of people who still seek better communication skills and more accessible professionals.

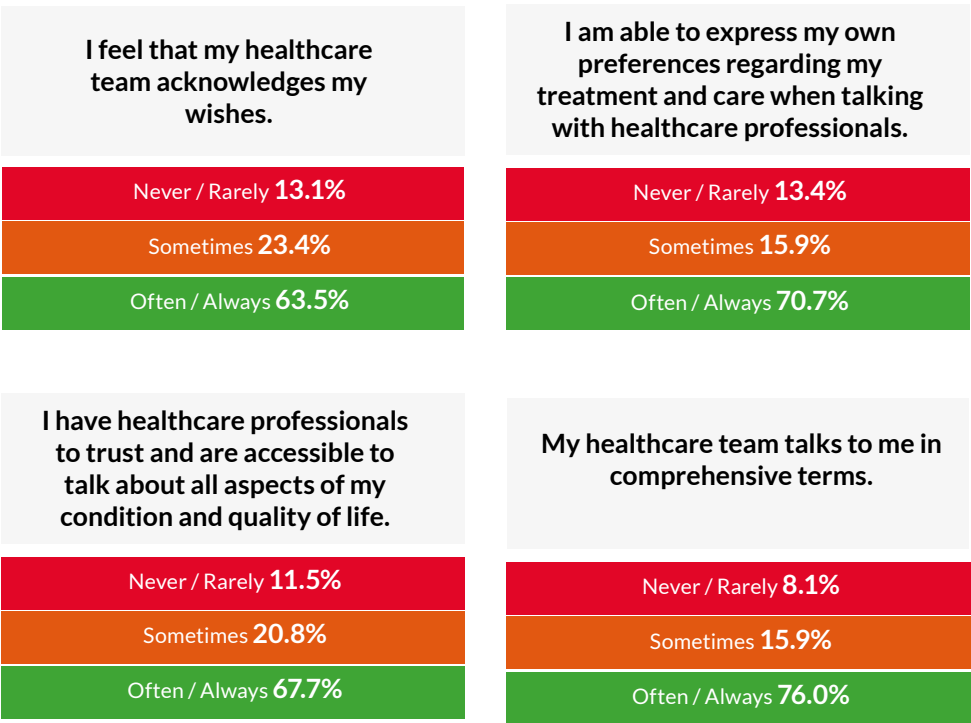


FIGURE 12. Communication with the healthcare team.

We found different experiences and opinions among people diagnosed with lung cancer who were interviewed regarding the support provided by healthcare professionals and the health system in general. Most reported satisfaction with the support received, however, some responses highlighted the need for improved communication to deal with the many challenges faced by those living with lung cancer.

“There were regular discussions about my condition and side effects and therefore I felt really supported throughout diagnosis and treatment”.

“I didn’t dare to ask the doctors for a lot of information about support, so I have felt supported mainly by the patients’ associations and my family”.

“

I have not felt helpless, but I had to deal with all the bureaucracy involved. I had to ask to be transferred to another hospital, which took a lot of time and effort, even though afterwards I was treated very well there. The problem is not the doctors but the bureaucracy that surrounds the healthcare system”.



c) Shared decision making.

This is defined as a process in which a healthcare professional works in collaboration with a patient to agree care decisions²⁷. It is important to involve people diagnosed with lung cancer in the decision-making process as this allows for a better psychological adjustment and an overall improvement in health-related QoL²⁸.

Figure 13 shows different items that assessed the level of involvement of participants in treatment decisions.

More than half of respondents stated that they participated frequently in treatment decisions, with their opinion considered by doctors. In contrast, it is remarkable that **1 of 4 people reported having little to no involvement in their care decisions, and 1 out of 5 felt that their opinion was never or rarely considered.**

Figure 14 shows that **72.2% of participants felt strongly that their opinion should be considered when deciding treatments options.** By contrast only 3.9% of respondents thought their preferences should not be considered. It is therefore a priority that people living with this disease are more involved in their treatment decisions, which has an additional positive impact on improving QoL (Fig. 14).

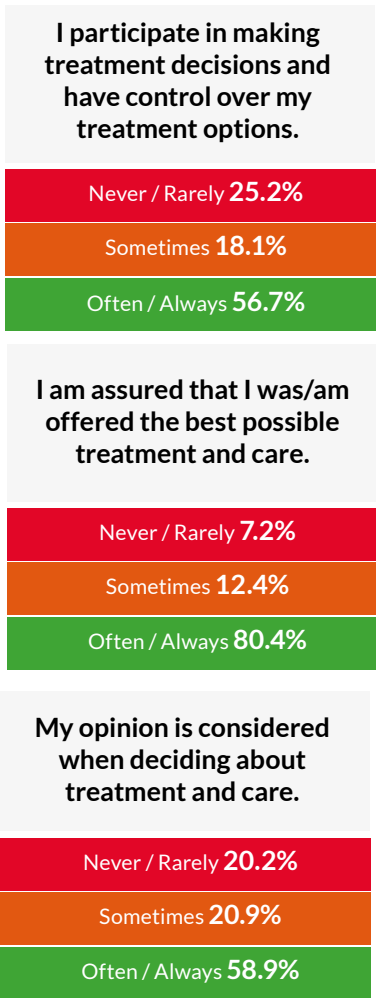


FIGURE 13.
Shared decision making.

Do you think that your opinion and preferences should be taken into account when deciding about treatments and care?

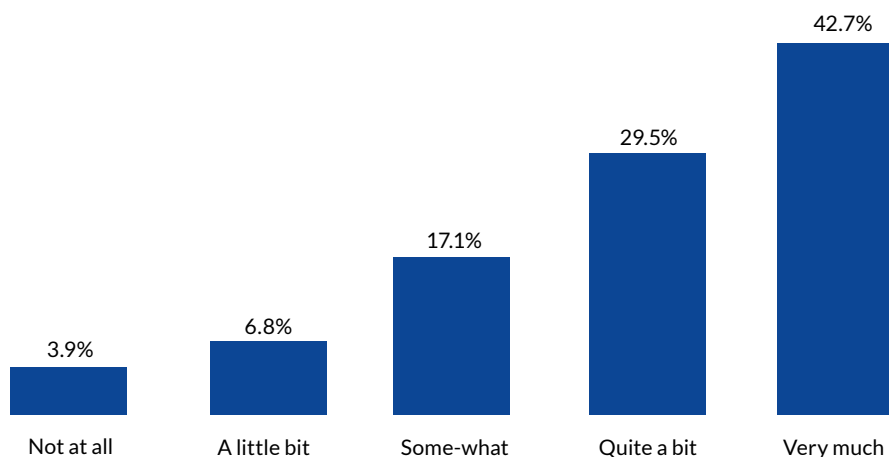


FIGURE 14. Opinion and preferences about treatment and care (n=468).

Further analysis of the domains (a. access and navigation of the healthcare system; b. communication with the healthcare team; c. shared decision making) indicates that people with primary education compared to people with secondary education were less inclined to be involved in their treatment decisions. This resulted in less favourable experiences overall when compared to people with tertiary education.

The eight people with lung cancer interviewed for this study, were asked about the 3 most positive and negative aspects about the healthcare they received. They lived in seven different countries in Europe and, therefore, seven different healthcare systems with a wide variation in lung cancer treatment and outcomes¹. Thus, we found little consensus in responses.



Positive aspects that were more frequently reported related to the support received by healthcare teams (5/8), access to effective treatments (3/8) and supportive care received to improve QoL (3/8).

Negative aspects that were more frequently reported related to communication difficulties with healthcare teams (3/8), lack of psychological support (2/8) and insufficient patient involvement in treatment and care decisions (2/8).



4.4. QUALITY OF LIFE AND WELL-BEING.

Despite the disease burden, **most participants acknowledged having a good QoL** at the time of completing the survey. 69.4% selected positive ratings of 5-7 (Scale 1 reflects very poor QoL and 7 reflects excellent QoL) (Fig. 15). These ratings are 20% higher compared to caregivers (Fig. 46). There were no differences in perceived QoL between people who were in active treatment and those who had completed treatment.

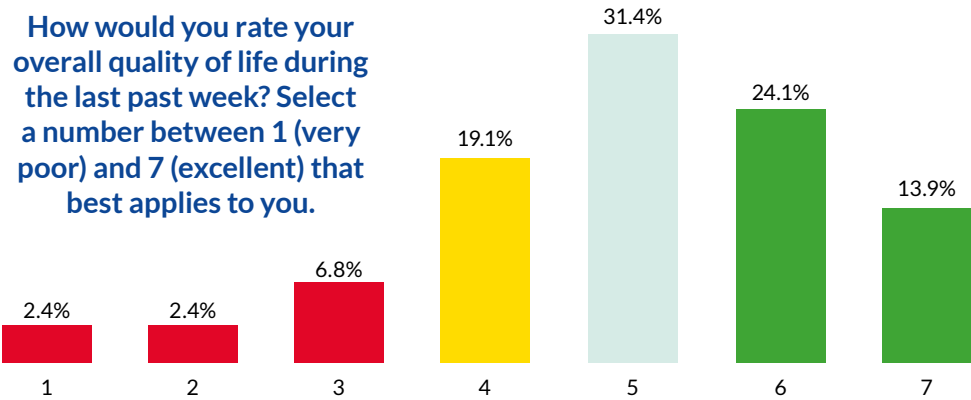


FIGURE 15. Quality of life (last week) (n=503).

People with lung cancer interviewed agreed that **QoL varies along the treatment pathway**. It is a dynamic journey and changes according to disease trajectory, treatment received and so on.

“I would say I’m currently on a 3, because it’s not something that’s constant. It depends on the chemo. I spend one week in bed after chemo, then I bounce back for another week and then there’s a week where I’m perfect until I start treatment again”.

“Current 6. Fortunately, now my health is stable”.

“I am now at a 6, however it varies depending on the treatment. I have been worse; I have had ups and downs depending on my health situation”.

“2-3 but it fluctuated throughout the whole process. My situation has changed a lot since diagnosis, especially after all the treatment”.

According to our survey, **the predominant variable that influences QoL is the impact of daily limitations**. There was a statistically significant correlation between the perceived QoL and the presence of limitations in daily activities ($p<0.05$) (footnote^f). Therefore, the greater the limitations in daily activities, the greater the effect on perceived QoL (Fig. 16).

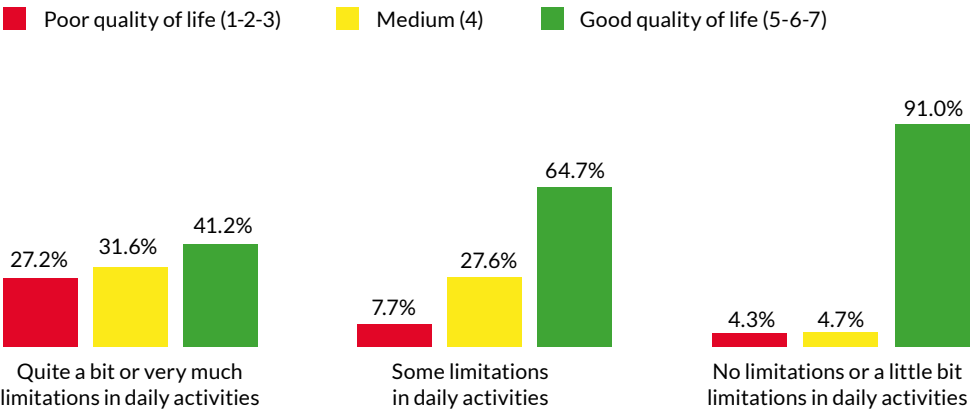


FIGURE 16. Daily limitations vs. quality of life.

QoL is influenced by the way each individual feels about their disease. As outlined in Table 4, lung cancer and treatments greatly impact both QoL and daily life activities.

Half of the participants (50.5%) recognised that they spent considerable time thinking about their disease and found their lives are dominated by treatment and test results (47.0%).

Despite these impacts, 65.5% of people stated they still had the ability to enjoy the things they usually did for fun and enjoy life (61.5%).

People with lower education levels reported more negative impacts on their lives in the five domains, however these differences were found not statistically significant ($p>0.05$) (footnote^f).

^f p value was calculated using inbuilt SurveyMonkey statistical tools.

Over the past seven days, how have you felt about the following?






| |  |  |  |  |  |
|---|---|---|---|--|---|
| | Strongly disagree | Disagree | Neutral | Agree | Strongly agree |
| I am able to enjoy life | 4.7% | 12.8% | 21.0% | 40.7% | 20.8% |
| I find my life is dominated by treatment and test results | 9.7% | 20.0% | 23.4% | 33.7% | 13.3% |
| I am enjoying the things I usually do for fun. | 3.4% | 12.1% | 19.0% | 45.3% | 20.2% |
| I spend much time thinking about the disease. | 6.9% | 22.0% | 20.5% | 37.2% | 13.4% |
| I don't feel like "myself" as I did before. | 8.8% | 15.9% | 18.3% | 35.4% | 21.6% |

TABLE 4. Experiences and feelings in daily life (n=511).

One of the factors that affect daily functioning and QoL in people undergoing active treatment and those in remission is cognitive impairment.

This might be due to the direct effects of the cancer itself, nonspecific factors, or comorbid conditions that are independent of the disease and/or adverse effects of treatments²⁹. Current evidence shows that an impact on cognitive ability is relatively common in people with lung cancer throughout the illness trajectory²⁶.

As Figure 17 shows, **most people (77.0%) reported that problems with memory, concentration or their thought process had interfered with their daily lives**, and its impact was *"quite a bit / very much"* in 1 out of 4 (25.4%).

To what degree have problems with memory, concentration or thinking interfered with your usual or daily activities?

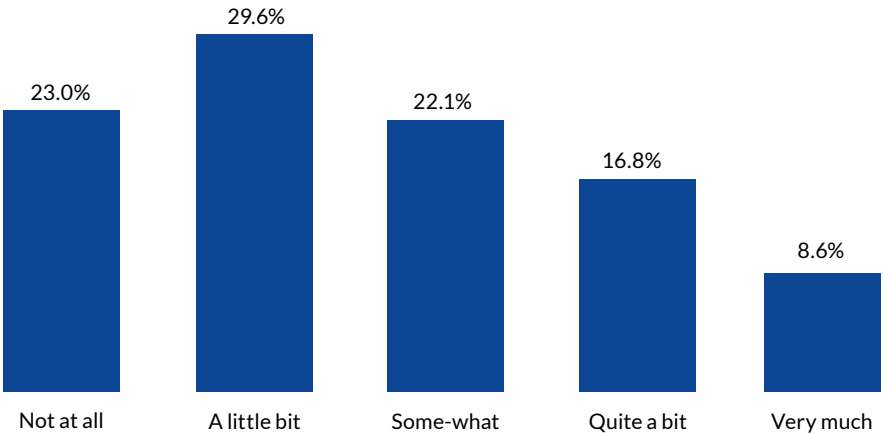


FIGURE 17. Impact of cognitive deterioration on daily life (n=453).

Cognitive impairment mainly includes memory deficits and distractibility. As Figure 18 details, **79.1% experienced difficulties in remembering things** (frequently experienced by 26.8%) and **73.7% concentration difficulties** (frequently experienced by 21.2%).



Have you experienced any of the following difficulties since diagnosis?

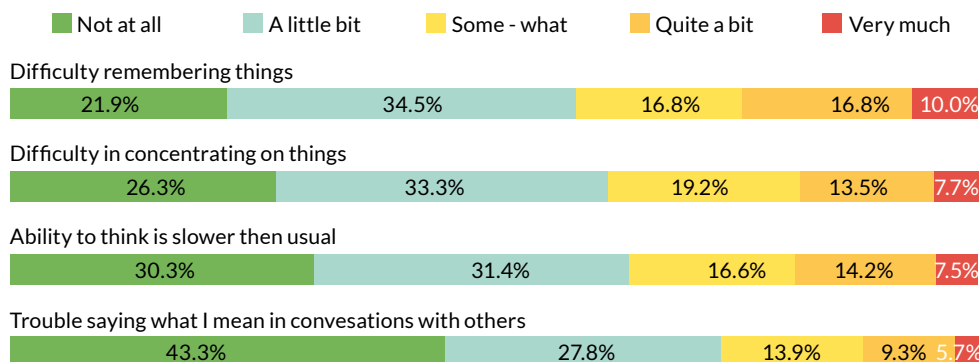


FIGURE 18. Cognitive impairments (n=453).

Although the development of brain metastases and treatment side effects contribute to the increase in risk of cognitive decline³⁰, evidence from our research does not indicate any greater neurological impact in this group of people, who demonstrated similar rates to other participants in the four items analysed.

| | | Difficulty remembering things (by quite a bit / very much) | Difficulty in concentrating on things (by quite a bit / very much) | Ability to think is slower than usual (by quite a bit / very much) | Trouble saying what I mean in conversations with other (by quite a bit / very much) |
|------------------------------|----------------|--|--|--|---|
| People with metastases in... | Brain | 21.4% (24 out of 112) | 27.9% (31 out of 111) | 35.1% (39 out of 111) | 16.1% (18 out of 112) |
| | Bones | 21.4% (27 out of 126) | 27.0% (34 out of 126) | 43.6% (34 out of 126) | 12.7% (16 out of 126) |
| | Liver | 22.4% (11 out of 49) | 28.6% (14 out of 49) | 34.7% (17 out of 49) | 14.3% (7 out of 49) |
| | Lymph nodes | 20.6% (37 out of 180) | 24.4% (44 out of 180) | 28.9% (52 out of 180) | 16.7% (30 out of 180) |
| | Adrenal glands | 23.9% (11 out of 46) | 32.6% (15 out of 46) | 37.0% (17 out of 46) | 21.7% (10 out of 46) |
| | No metastases | 18.8% (15 out of 80) | 17.5% (14 out of 80) | 18.7% (15 out of 80) | 13.7% (11 out of 80) |

TABLE 5. Neurological impact in people with and without metastasis.

According to the literature, **one of the most consistent needs of people with lung cancer is being informed about things they can do to improve health outcomes²⁶**. This includes being informed about self-care and lifestyle factors, such as exercise, diet or rest.

Healthy behaviours and lifestyle factors play an important role across the continuum of care⁴. However, our findings show that **exercise, nutrition and resting time have been negatively affected after diagnosis for most people with lung cancer**.

More than half (55.1%) had reduced their physical activity level since diagnosis. This reduction was greater in people with metastasis: 63.2% of people with bone, 58.6% with brain and 58.3% with lymph node metastasis experienced reduced

physical activity to a greater extent, in comparison to people without metastasis (43.2%).



Have you reduced or increased your physical activity levels since diagnosis?

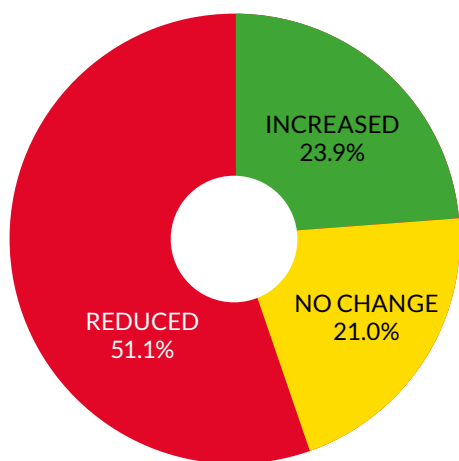


FIGURE 19. Impact on physical activity levels (n=452).

The three main barriers for physical exercise were related to side effects or symptoms: fatigue (65.8%), breathlessness / cough (51.8%) and pain (31.3%).

Fatigue is the main barrier to performing exercise. However, several studies have shown that physical activity is associated with improvements in fatigue, QoL and functional capacity³¹⁻³².

It is also important to offer rehabilitation services to help people deal with symptoms i.e. breathlessness and cough. These are the second most cited barriers to performing exercise (Fig. 20). Pulmonary rehabilitation programs for postoperative people with lung cancer have demonstrated improvements in functional ability and a greater adherence to exercise³².

Exercise intervention pre-operatively or post-cancer treatment is associated with benefits of improved physical capacity, symptoms and QoL⁴⁻³¹.



“Physiotherapy has provided me guidelines to exercise that increased breathing volume and helped maintaining my physical strength. Otherwise, all fitness depends on your own motivation”.

Have you ever experienced the following difficulties to physical exercise since diagnosis?

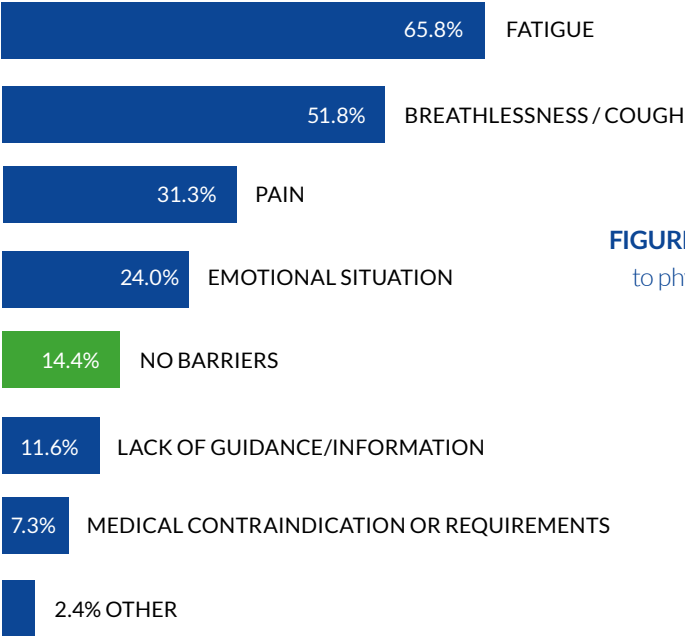


FIGURE 20. Difficulties to physical exercise (n=450).

People receiving cancer treatment are at increased risk of experiencing nutritional concerns, may develop eating issues and other gastrointestinal difficulties. Weight loss is common, affecting QoL and can be a distressing sign of disease progression¹¹. Good nutrition is essential for people with lung cancer, so a systematic nutritional assessment is required as well as a follow-up review²⁰.

Nutrition is one of the main concerns and unmet needs for people with lung cancer. According to Table 2 (Symptoms and side effects), 49.5% of participants reported **eating difficulties** and 1 out of 10 acknowledged a high impact on their QoL. However, when asked about how eating and drinking had been affected (Fig. 21), the percentage of people who reported to be affected was higher at 55.0%. The **main issues reported were dry mouth (21.3%), taste or smell changes (20.4%) and appetite loss (19.7%)**.

How your eating and drinking have been affected since diagnosis?

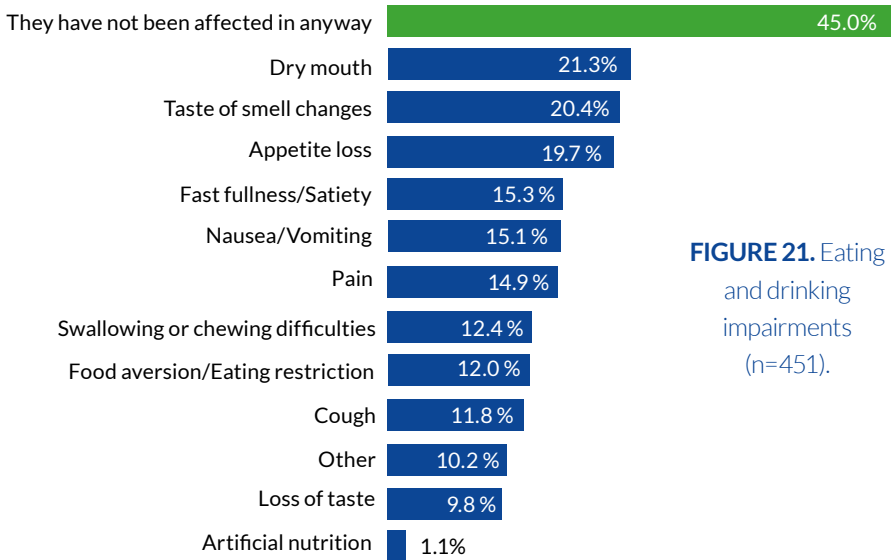


FIGURE 21. Eating and drinking impairments (n=451).

Nutritional intervention or counselling is one of the main priorities reported by participants: 31.5% missed information and support on nutrition and exercise. According to the 5th LuCE Report (2020), 1 out of 4 patients expressed interest in receiving specialised dietary advice²⁴.

Previous evidence has highlighted that the most frequent sleep disorders in people with cancer are insomnia, hypersomnia and circadian rhythm disorders (sleep-wake cycle is not properly aligned with the environment)³³. Most participants expressed that they experienced sleep difficulties, the second most common side effect that impacted QoL (see Table 2: Symptoms and side effects).

When asked about the reasons behind sleeping concerns, **6 out of 10 reported that worries and intrusive thoughts were the most prominent issues which interfered with sleep.** This appears to be a major reason relating to sleep disturbances. Other reasons cited were nocturia (28.4%) and pain (27.9%) (Fig. 22).



Further investigation into sleep disturbance issues is required to improve health, survival, response to therapy and reduction of comorbidities³³. Increased efforts should be taken to improve sleep quality in order to improve QoL.

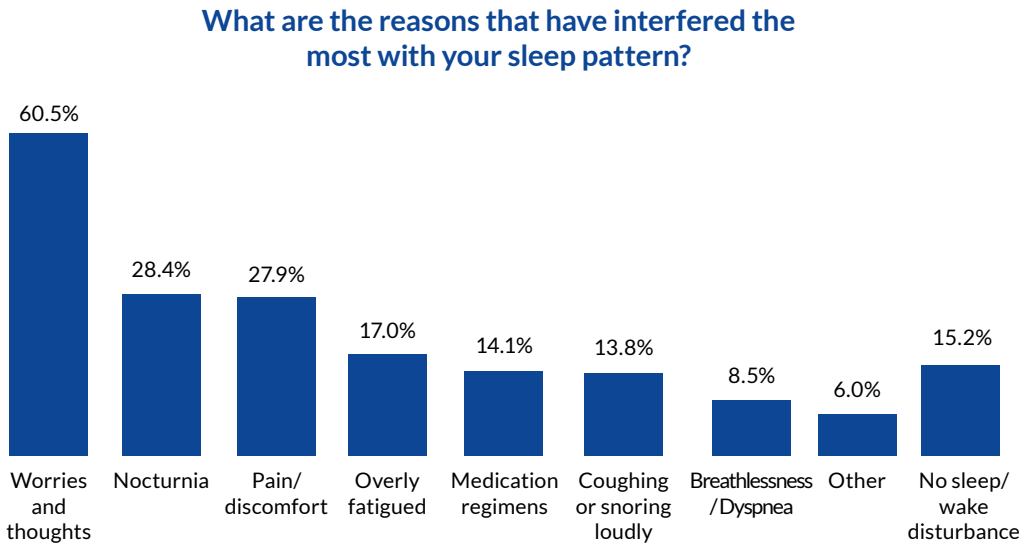


FIGURE 22. Reasons that interfered in sleep pattern (n=448).



Most participants reported an impact on sexual relationships and 1 out of 4 (24.9%) stated that this impacted *‘quite a bit / very much’* on their QoL (see Table 2: Symptoms and side effects).

Previous research identified both negative and positive effects of cancer on intimacy and sexual intercourse²¹.

According to our participants, the **impact on sexual intimacy was more negative than positive**, and for 52.9% sexual intercourse was most affected with respondents reporting a *‘negative / very negative’* impact.

A further 31.3% experienced a negative impact on emotional intimacy (mutual appreciation, feelings of comfort, sensitivity, empathy, etc.) and 24.8% on physical intimacy (holding hands, hugging, kissing, caressing, etc.) (Table 6).

Regarding sexuality and intimacy, have you experienced any impact on the following?

| | Emotional intimacy | Physical intimacy | Sexual intercourse |
|---------------|--------------------|-------------------|--------------------|
| Very positive | 6.0% | 8.4% | 1.9% |
| Positive | 15.1% | 14.2% | 2.8% |
| No change | 47.6% | 52.6% | 42.4% |
| Negative | 20.2% | 17.1% | 33.3% |
| Very negative | 11.1% | 7.7% | 19.6% |

TABLE 6. Impact on sexuality and intimacy (n=436).

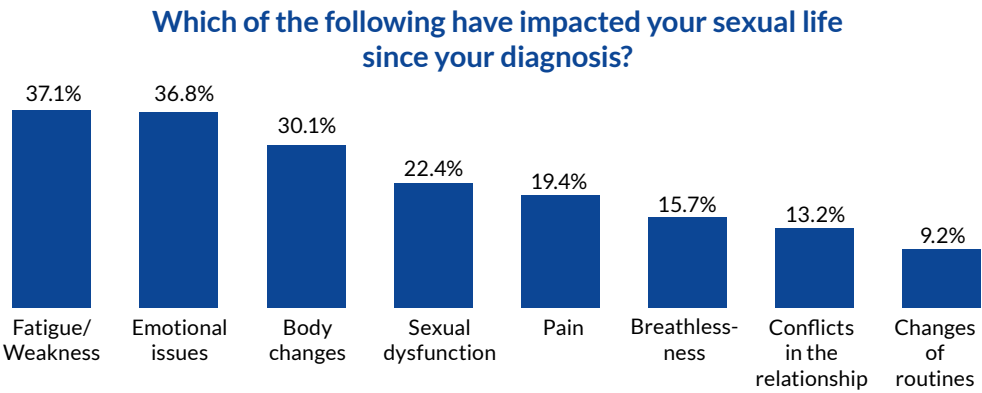


FIGURE 23. Difficulties to sexual life (n=402).

Once again, **fatigue** was reported by a significant group (37.1%) of people as a primary reason for the deterioration of their sexual life. A similar percentage (36.8%) reported **emotional issues** and (30.1%) **body changes**. Also reported were sexual dysfunction issues. According to the literature, these include atrophic vaginitis and stenosis (among women) and erectile dysfunction (among men)³⁴.

There are **significant differences in sexual issues reported between male and female respondents** (Table 7).

Women highlighted body changes and pain to a greater extent, while men reported fatigue and sexual dysfunction as the major impacts on their sexual life.

| | Women | Men |
|--------------------|-------|-------|
| Fatigue | 33.7% | 47.0% |
| Body changes | 35.4% | 15.0% |
| Sexual dysfunction | 16.5% | 40.0% |
| Pain | 23.6% | 8.0% |

TABLE 7. Gender differences in difficulties to sexual life.

4.5. END-OF-LIFE DECISIONS AND CARE.

Discussing end-of-life decisions, desires and concerns with family and loved ones is very important. It is an opportunity to make arrangements that suit a person's values and wishes, as well as a chance to reflect on what is important for them.

However, from our report findings, a little over a third of participants (37.2%) had fully shared their feelings and only 35.9% had fully discussed their preferences regarding end-of-life care with their family and loved ones.

Table 8 shows that **36.6% would have liked to share their feelings within their support network** to a greater extent. Similarly, **44.2% would have liked to discuss their preferences** regarding end-of-life decisions to a greater extent.

| | Yes | Yes, but not enough | No, but I would like to | No, because there is no need | No, I prefer not to |
|--|-------|---------------------|-------------------------|------------------------------|---------------------|
| Have you ever shared your feelings about end-of-life within your support network? (n=352) | 37.2% | 22.7% | 13.9% | 12.8% | 13.6% |
| Have you ever discussed your preferences regarding end-of-life decisions with your family/ loved ones? (n=351) | 35.9% | 34.8% | 9.4% | 10.3% | 9.7% |
| Have you ever discussed your preferences regarding end-of-life decisions with your healthcare team? (n=354) | 8.8% | 11.6% | 32.2% | 35.0% | 12.4% |

TABLE 8. Communication regarding end-of-life.

End-of-life care discussions between people with cancer and their care team is important, however discussions on death are still taboo for many, or at least a topic not commonly discussed³⁵. The lack of end-of-life discussions is associated with increased frequency in the use of aggressive care, poorer patient satisfaction, worse psychological morbidity and lower QoL³⁶.

Planning discussions should be moved to the forefront during treatment decision making and continued throughout the course of care³⁷. However, **only 8.8% of participants have fully discussed their preferences regarding end-of-life-care** decisions with their healthcare team.

Approximately half of the participants affirmed that they had never had such a discussion, as 35.0% felt there was no need and 12.4% preferred not to. It is particularly significant that **1 out of 3 participants (32.2%) had not discussed end-of-life, even though they would have liked to**.

Communication is crucial to know and understand a person's values, priorities and decisions regarding their end-of-life care. It helps to reduce uncertainty concerns, respect their wishes and decrease the family burden.

“

“My greatest fear is that I will die disabled, with pain, without adequate protection with painkiller”.

“

“I’m concerned that they won’t respect my decisions in the final moments”.

“

“I worry that they don’t follow my wishes and I am not able to control the situation”.



Principles and steps in communicating when discussing end-of-life issues (Clayton et al. 2007)³⁸

- P** Prepare and understand all the updated information on the patient's condition.
- R** Rapport: relate to person; show empathy and compassion.
- E** Expectations: elicit their expectations and preference for information.
- P** Provide information in simple, clear language.
- A** Acknowledge emotions and concerns.
- R** Realistic hope.
- E** Encourage questions.
- D** Document discussion in medical records.

FIGURE 24. Principles when discussing end-of-life issues.

Understanding the wishes and concerns of those living with lung cancer is important to ensure appropriate support and information is provided and to ensure their decisions are respected.

The majority of participants indicated that there were two **main practical supports required: comfort and dignity (78.8%), and symptom management (73.1%).**

Clinicians need to pay special attention to the physical distress caused by lung cancer during end-of-life care and to optimise comfort and dignity. Open discussions with healthcare professionals may help to reduce fears related to end-of-life care.

One of the main challenges is that, even when a majority of people with lung cancer require high-quality end-of-life supportive care, these specialised units are not available and accessible at all locations¹.

What practical supports do you think would help you the most when deciding on end-of-life care?

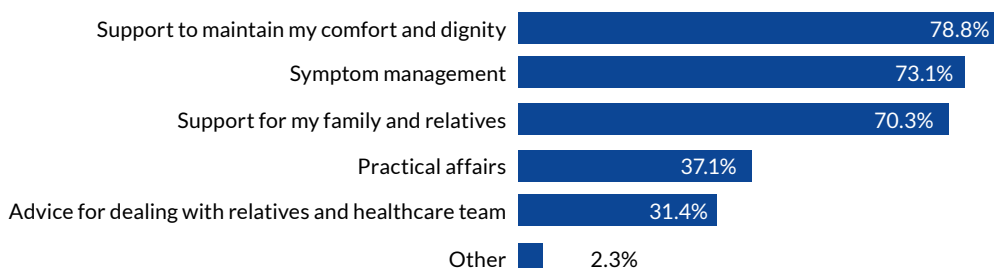


FIGURE 25. Support on end-of-life care (n=353).

5. RESULTS: People caring for someone with lung cancer

5.1. DAILY LIFE AND CAREGIVING.

Caregivers play a critical role in navigating the day-to-day experiences for those living with lung cancer²⁸.

Being a caregiver is not only about performing one specific task or taking responsibility for certain things, it is about supporting many different issues, as Figure 26 shows.

The four most common issues were emotional support (88.5%), attendance at medical appointments (83.4%), help with care and treatment decisions (74.3%) and taking care of the housework and shopping (73.9%).

What type of support have you usually provided to your loved one?

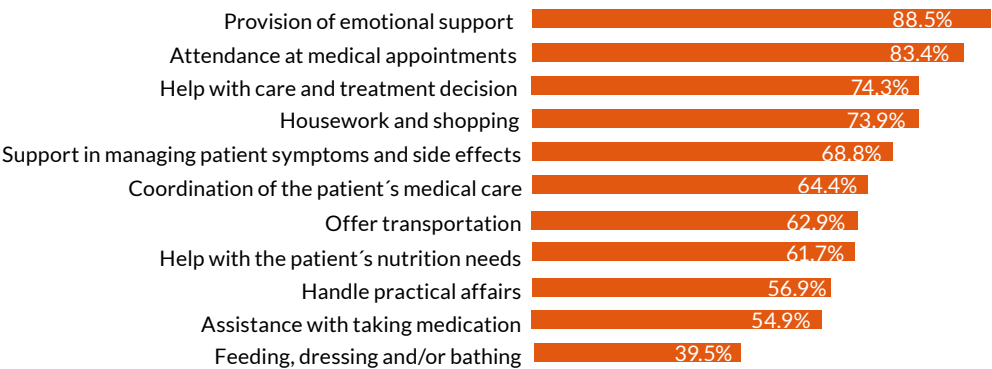


FIGURE 26. Support provided by the caregiver (n=253).

“The challenge was to bring the psychological support to my partner and to provide an easy daily life”.

“We had to rearrange our habits around my mother’s necessities. It’s about coordinating everything to make it work”.



“We had to accelerate diagnostics, look for treatment options and coordinate care throughout the course of the disease”.

“The first one was to support him in every way possible in order to save his life. The second was to face the bureaucracy of government procedures and to work with the doctors”.

The high physical and psychological experience makes lung cancer especially distressing for caregivers³⁹. They need to balance care demands with their own feelings and experiences when caring for their loved one throughout the course of the disease.

The routine of daily life is altered to adjust and respond to the demands of the disease: **88.6% acknowledged some limitations in daily life** related to caregiving. It is important to note that **1 out of 4 caregivers (27.3%) have experienced high limitations** in their daily life (*quite a bit/very much*) (Fig. 27).

As caregiver, have you experienced limitations in daily activities related to caregiving?

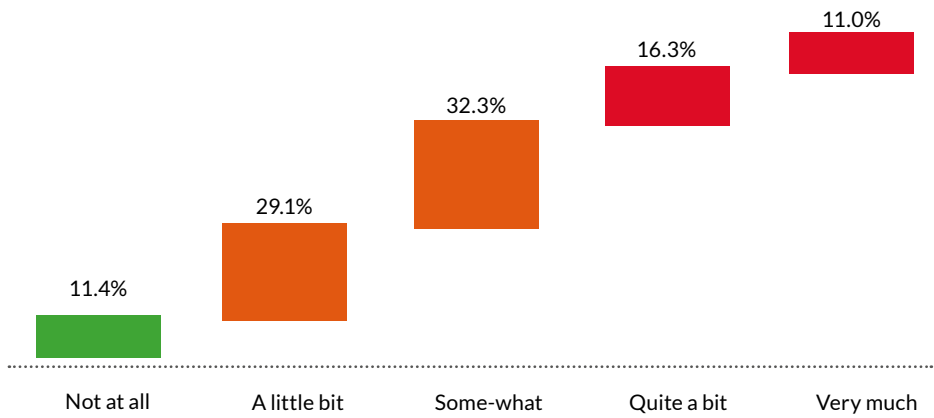


FIGURE 27. Daily limitations related to caregiving (n=282).

Caregivers face different challenges every day in meeting their loved ones needs. **Their own emotional concerns (63.1%) had the most effect on their daily activities**, followed by treatment requirements (54.1%) and caregiving responsibilities (49.1%), as shown in Figure 28.

In case you have ever experienced limitations in daily activities related to lung cancer and treatments, what have been the reasons?

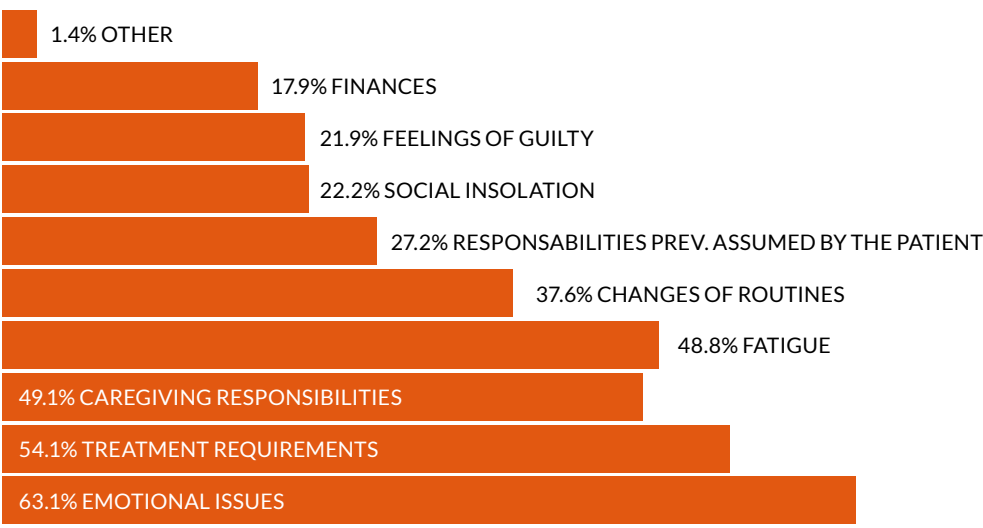


FIGURE 28. Reasons of daily limitations (n=279).

Caregivers interviewed were asked about major changes in their daily life after their loved one's diagnosis. Overall, **7 out of 8 specified that their routines completely changed because of treatment and caregiving requirements**, and explained how their priorities had changed to focus on caring for their loved one.

“

“Life turned 360 degrees and the priority was to fight for the patient's life.”

“

“Mainly what changed was our daily routine as we had to adapt our schedules to my uncle's hospital visits.”

“

“I basically abandoned everything to take care of him, so I stopped having a private life, my work, everything.”

“

“Now I dedicate myself to her, if I have to take her to the doctor, then we go together, and so on.”



Impact on daily life was associated with disease burden and respondents reported significant deterioration in different aspects of their lives. More than a half of caregivers identified impacts in the following areas: future plans, lifestyle, family life, independence, work and finances (Fig. 29).

In addition, **future plans were highly impacted in 57.8% of participants. Lifestyle (50.5%) and family life (45.0%) were likewise impacted.** Moreover, it is remarkable that participants reported that work and finances were affected *‘quite a bit / very much’* in 29.4% and 24.6% of the cases, respectively.

To what degree have the following areas of your life have been affected since your loved one's diagnosis?



FIGURE 29. Areas of life affected since the patient's diagnosis (n=282).

Caring for a person with a diagnosis of lung cancer can be a challenging experience both physically and emotionally.

According to Table 9, **79.4% of caregivers confirmed that they spent a lot of time thinking about the disease** (this was reported by 50.6% of people with lung cancer) and **65.9% acknowledged feeling that their life was dominated by treatment** and test results (this feeling was reported by 47.0% of people living with lung cancer).

It seems that the experiences of the disease are different among caregivers, compared to those diagnosed with lung cancer. Only a minority of caregivers stated that they enjoyed the things that they usually did for fun (40.7%) and were able to enjoy life (31.2%). These percentages are much higher among people with lung cancer: 65.5%, and 61.5%, respectively.

Over the past seven days, how have you felt about the following?






| |  |  |  |  |  |
|--|---|---|---|--|---|
| | Strongly disagree | Disagree | Neutral | Agree | Strongly agree |
| I am able to enjoy life. | 11.5% | 19.3% | 38.0% | 24.4% | 6.8% |
| I find my life is dominated by treatment and test results. | 2.5% | 11.0% | 20.6% | 43.8% | 22.1% |
| I am enjoying the things I usually do for fun. | 11.8% | 18.6% | 28.9% | 33.9% | 6.8% |
| I spend much time thinking about the disease. | 2.5% | 6.0% | 12.1% | 46.3% | 33.1% |
| I don't feel like "myself" as I did before. | 3.9% | 11.7% | 20.6% | 39.2% | 24.6% |

TABLE 9. Experiences and feelings in daily life (n=282).

5.2. THE EXPERIENCE OF CAREGIVING.

People who care for someone with the disease can experience profound challenges after diagnosis. Some factors that contribute to increased distress include dealing with practical tasks, managing a loved one's emotional issues, facing the possible prospect of losing their loved one, and coping with an uncertain future⁴⁰.

This experience is associated with an increased mortality risk for caregivers⁴¹ and primary caregivers are affected to a greater extent. 85.6% of survey respondents were primary caregivers, and 34.4% said that they were the sole companion supporting the patient. Being the sole caregiver is an important factor that can negatively influence their experience⁴².

Asked about what issues were **most stressful in their experience**, as Figure 30 shows, a majority of respondents reported **dealing with declining health** (70.6%) and **providing emotional support** to the person diagnosed with the disease (69.8%) were the greatest concerns. Poor management of symptoms complicates care and contributes to the challenges that caregivers experience, especially as the disease progresses⁴³.



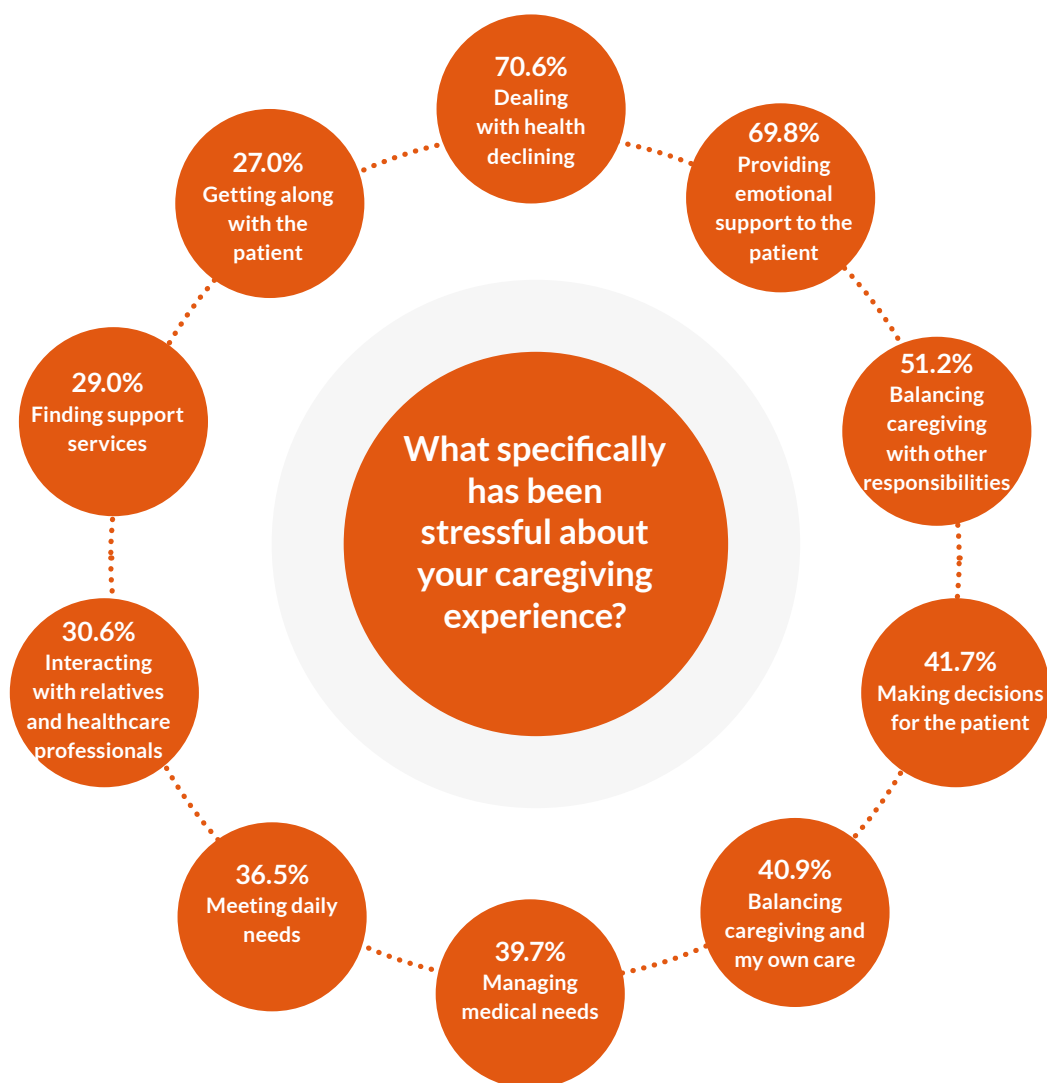


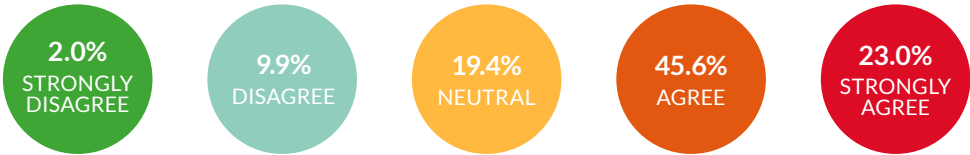
FIGURE 30. Stressful issues related to caregiving (n=253).

Caregivers experienced high levels of subjective stress and **most participants (68.6%) stated that they felt the well-being of their loved one was highly dependent on them.**

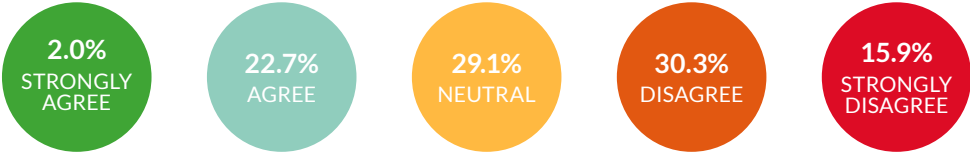
Thus, the feeling of not having time for themselves and the sense of having lost their personal privacy were frequently highlighted (46.2% and 30.7%, respectively).

On the other hand, the perceived experience depends on how they assess and value their own ability to meet the caregiving demands⁴⁴. **60.9% answered that they were satisfied with the care and support they provided.** However, only 34.1% of people surveyed felt supported in their role as caregiver (Fig. 31).

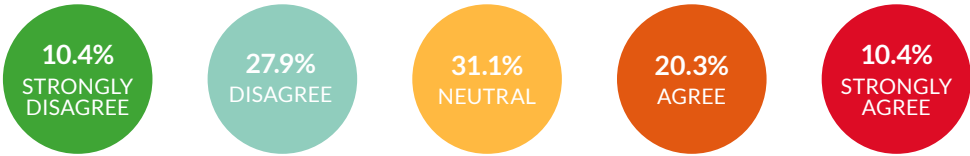
I feel that the well-being of the patient highly depends on me.



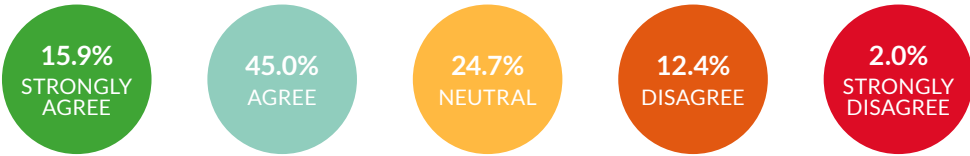
I have time for myself.



I have lost my personal privacy.



I am satisfied with the care and support I provide.



I feel supported in my role as caregiver.

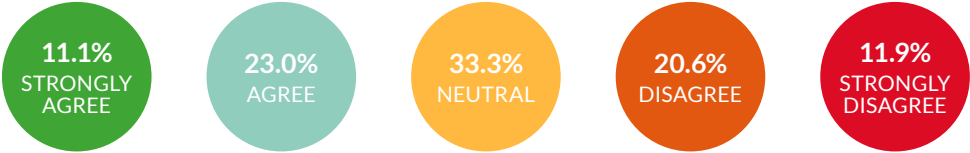


FIGURE 31. Experience of caregiving.

Asked about how they valued their experience providing care to people with lung cancer, **caregivers interviewed highlighted** the complexity of their experience for which **no one prepares you for**, and how it is different and unique to other life experiences (4/8). Caregivers also reported issues related to **caregiving demands** and specific challenges they had to face during the disease (4/8). Finally, the experience of caregiving is also associated with **resilience and learning** (3/8).

“

“It’s something that you have never experienced before, it was something I was not prepared to live with. I tried to manage the whole situation but I didn’t have the support to cope with what was happening”.

“

“At the beginning she needed a lot more than she needs now, she needed me permanently and sometimes I felt a bit lonely. But now, little by little, she started to get stronger”.

“

“The experience was complex: hard because I had to support my partner while I was very worried for him, good because I discovered I had the strength to do it”.

“

“It was one of the hardest experiences in my life. This was one of the toughest experiences I’ve had to face in my life”.

“

“It was very difficult and demanding to coordinate treatment and care for the patient”.

“

“At the beginning it came like a shock, we didn’t know how to react, but we eventually learned to adjust”.

Caregiving has an impact on the health of those who provide support. This can affect not only their emotional state, but also a decline in their own physical health.

82.3% of respondents reported some physical health deterioration since they started caregiving, 18.8% stating that this impact was ‘quite a bit / very much’ (Fig. 32). This does not mean that deterioration was a consequence of the caregiving in all cases, but it represents an additional difficulty that caregivers may experience.

Have you experienced deterioration in your physical health since your loved one was diagnosed with lung cancer?

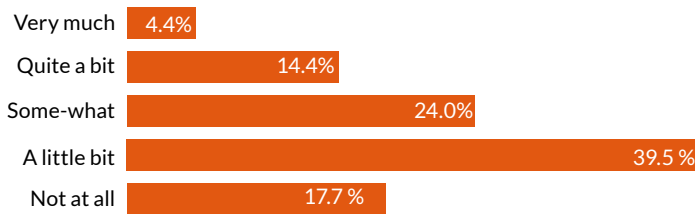


FIGURE 32. Deterioration in caregiver physical care (n=271).

Different physical health problems have been associated with caring for people with lung cancer⁴⁵. Our findings show that people with lung cancer and caregivers report the same two physical problems as mostly impacting their lives: **fatigue and sleep disturbances** (Fig. 33).

Have you experienced any of the following physical problems since you started caregiving?

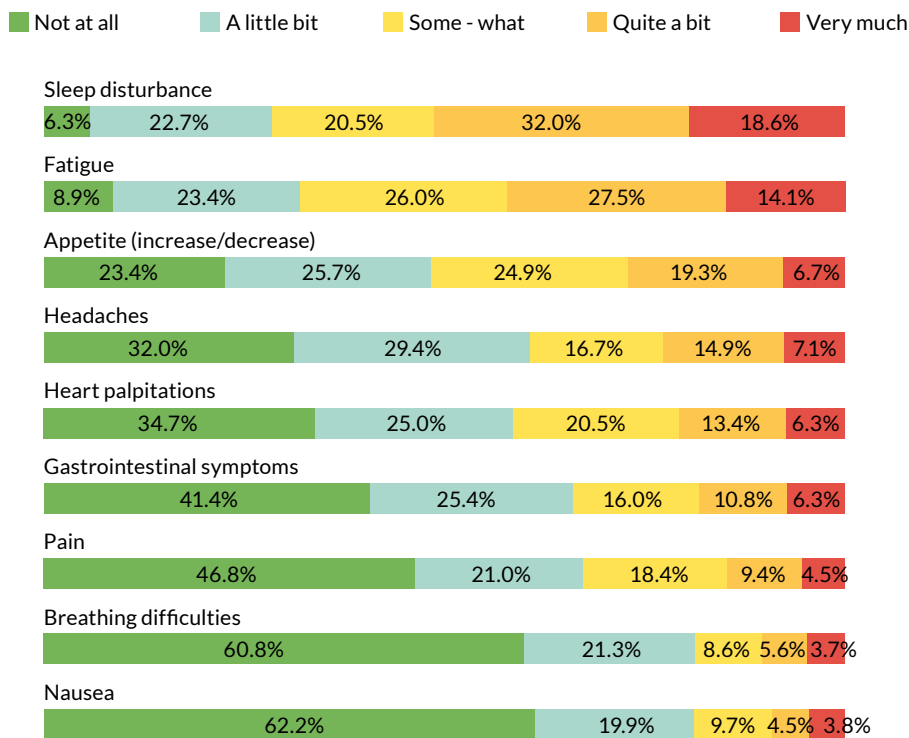
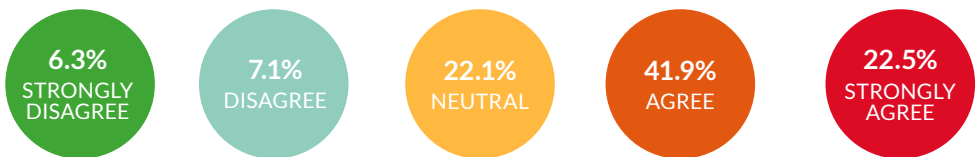


FIGURE 33. Physical problems since caregiving (n=270).

Almost all caregivers (94.7%) had experienced sleep disturbances, and previous research has shown that these are associated with other difficulties, mainly fatigue³². This has been reported by 9 out of 10 caregivers (91.1%) as *‘quite a bit / very much’* to 41.6% (Fig. 33). Women reported a much higher impact of fatigue (46.1%; 102/221) than men (20.9%; 10/48).

Thus, 64.4% stated that they often felt physically exhausted. We should remember that, as it was shown in Figure 28 (*Reasons of daily limitations*), 48.8% of caregivers point out how fatigue resulted in limitations to their daily activities, so it is an urgent priority to address this important issue to improve caregivers' experience and QoL.

I often feel physically exhausted



5.3. HEALTHCARE AND INVOLVEMENT IN TREATMENT DECISION PROCESS.

People living with lung cancer sometimes rely on their caregivers for support for daily activities or issues relating to the disease. As Figure 26 (*Support provided by the caregiver*) shows, many caregivers are directly involved throughout the disease, for example attending medical appointments, helping with care and treatment decisions, or coordinating medical care, among other things. Also, they contribute to maintaining the well-being of their loved one in helping to manage side effects or providing emotional support, and so on.

Despite this critical support from caregivers, **only a few (11.5%) said they**

“I didn't feel supported in coping with the challenges, I had to get to everything on my own”.

“On a medical level, we have all the attention we could have asked for, we did not need needed more”.

“There is a clear lack of information and support for the patients, there is no one you can call when you need that support”.

received support from healthcare professionals in delivering the best care possible to their loved ones (Fig. 34).

Our results show that caregivers very often feel unsupported by healthcare professionals. In their role of caregiving, these individuals can experience health decline themselves.

More than half (56.2%) reported that they did not receive any support to maintain and improve their own health and QoL, and only 10.4% said they received support frequently (Fig. 35).

According to most caregiver interviews, family is the main source of help and there is a significant lack of support from the healthcare system.

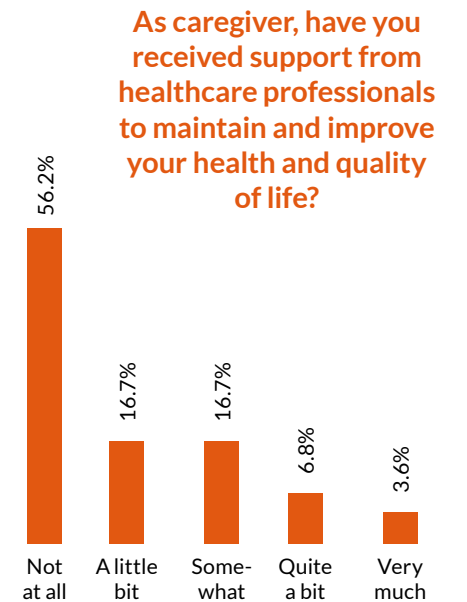


FIGURE 35. Support from healthcare to offer best care (n=253).

Have you received support from healthcare professionals to learn how to offer the best care as possible to your relative?

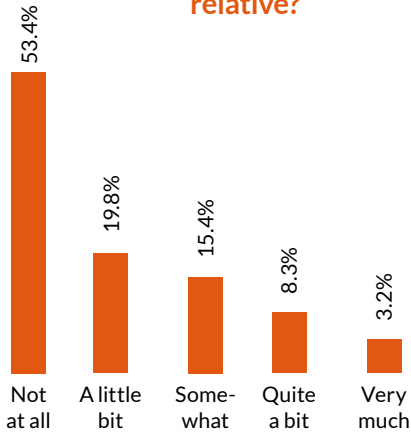


FIGURE 34. Support from healthcare to offer best care (n=253).

Caregivers’ perceived preparedness is associated with experience⁴⁶, thus, it is necessary to implement interventions to improve their QoL. There are two main reasons that may explain the lack of support for caregivers: Firstly, healthcare professionals are focused primarily on the physical needs of the person with the disease⁴⁶, and secondly caregivers often avoid asking for help.

Half of the participants (49.8%) recognised having asked for help rarely or never (Fig. 36). The reason most frequently reported was that **they did not want to worry their loved one about their own needs (53.0%)**. In terms of healthcare, **20.5% felt there was no one available to help** and 16.3% stated difficulties in expressing distress to healthcare professionals (Fig. 37).

Have you asked for help when you needed it?



FIGURE 36. Request for help when needed (n=253).



FIGURE 37. Reasons for not asking for help (n=215).

Many caregivers neglect their own health: **36.9% of participants acknowledged that they have not attended all their own medical appointments** (Fig. 38).

Even when a majority continues attending these consultations, there is an urgent need to raise awareness of the importance for caregivers to self-care and to attend regular medical check-ups. **Female caregivers reported higher unattendance** (39.8%; 88/221) than male careers (24.0%; 12/50).

“My mother needed a surgery, but she decided to postpone it because she needed to be with my father’.

Have you attended all your regular medical appointments?

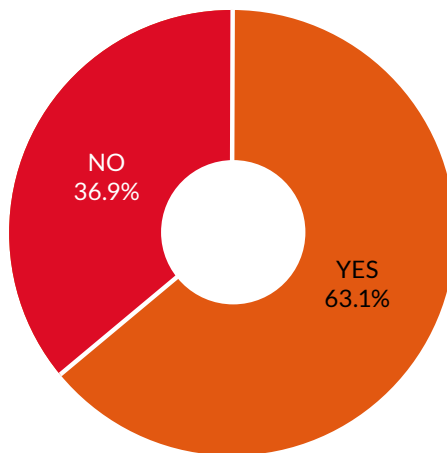


FIGURE 38. Attendance to medical appointments (n=271).

Most caregivers neither received help from healthcare professionals nor did they demand support for themselves. However, this does not mean that there are no unmet supportive needs. **84.4% of participants identified at least one information or support need** (Fig. 39). The most frequent needs related to psychological counselling, help to deal with side effects, and medical information.

What type of information/support have you missed?

TOP-PRIORITY.

- 51.9%** Psychological counselling
- 41.6%** Side effects (and how to manage)
- 41.6%** Medical information

OTHER IMPORTANT TOPICS

- 31.3%** Health system navigation
- 30.9%** Social resources and rights
- 27.6%** Patient organisations, peer support and non-profit organisations
- 25.1%** Nutrition and exercise

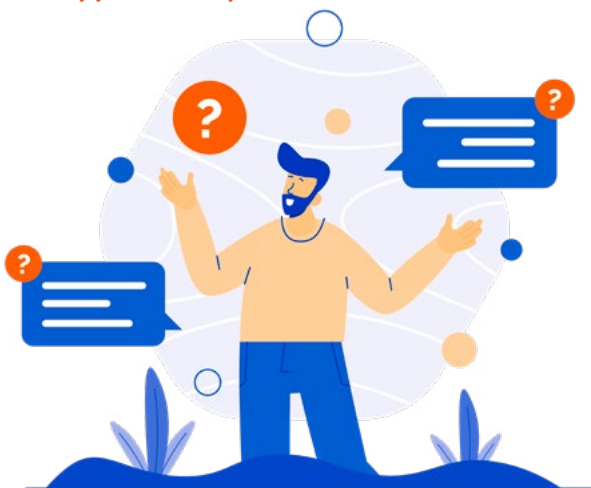


FIGURE 39. Information / Support most missed (n=243).

“

There are no specific resources for us as caregivers. There should be a person or a unit in the hospital, someone like a social worker of some kind, who can lend a hand to the caregivers. Someone to help us through the whole process, to give us the information and guidance we need to face everything that lies ahead in terms of helping the patient”.

Regarding medical information, our research shows the active role of caregivers in the treatment decision process (Fig. 40) and that they accessed a high level of information along the course of the disease (Fig. 41). **8 out of 10 were directly involved in treatment decisions** and 32.2% were the primary decision-maker (Fig. 40). Our data suggests that female caregivers are much more involved in treatment decisions than men (83.7% -170/203- vs. 69.0% -29/42-, respectively).

As a caregiver, how involved, if at all, are you in treatment decisions?



FIGURE 40. Level of involvement in treatment decisions (n=245).

Most caregivers (91.4%) had received medical information about diagnosis, treatment and test results (44.7% by 'quite a bit / very much') (Fig. 41).

As caregiver, have you received all the information you needed about the diagnosis, treatment and test results?

“

I don't have a high level of education, so for me to understand all of this was very difficult. Thankfully, I had 2 navigators who helped me a lot during these times”.

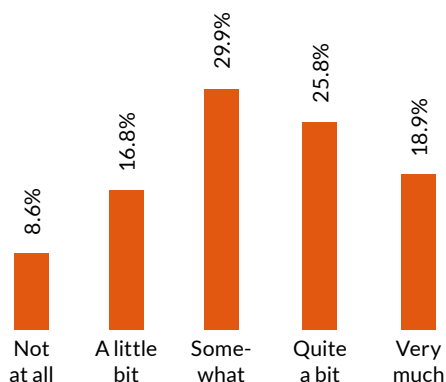


FIGURE 41. Medical information received (n=244).

Caregivers play an important role in communicating with healthcare providers and representing their loved one's interest in treatment and care decisions. These responsibilities can increase their stress, especially when caregivers need to make difficult choices on their own⁴⁷.

Communication between people living with lung cancer and caregivers is crucial. However, **44.3% of caregivers had guarded medical information** to protect their loved one and **77.3% acknowledged to have hidden their feelings** and concerns about the disease (Fig. 42).

Caregivers sometimes hid information from their loved ones, but more than half (53.7%) also thought that the person diagnosed with lung cancer did not fully share symptoms and/or side effects with them. Figure 10 (*Symptoms and side effects reported by patients*) shows that 39.3% of people with lung cancer acknowledged that they did not share all symptoms and side effects with their relatives.

Most participants (64.8%) reported that communication was a challenge and they found it difficult to talk to their loved one about their disease (Fig. 42).

“

The main challenge was to try not to show the fear I had; I didn't want her to fall apart emotionally”.

Talking about information and communication with your loved one, have you experienced the following situations?

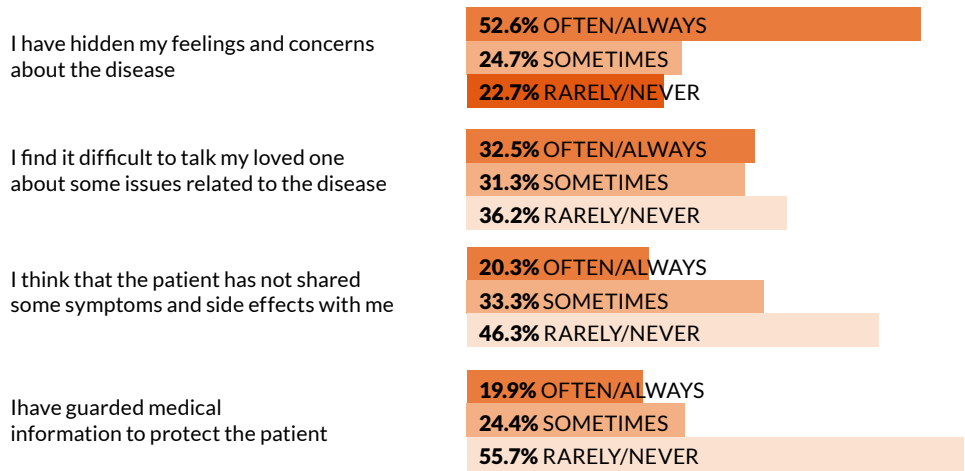


FIGURE 42. Communication with the patient (n=247).

There are different levels of involvement, and we have observed that most caregivers are highly involved in medical decisions. The next figures show that **57.5% were satisfied with their level of involvement** (only 10.5% were unsatisfied) (Fig. 43). On the other hand, there are very different opinions about whether their opinion should be considered in their role as caregivers: 27.3% thought their input should be considered, and 43.7% responded *'not at all / a little bit'* (Fig. 44).

How satisfied are you with your level of involvement in the treatment and care decision process?

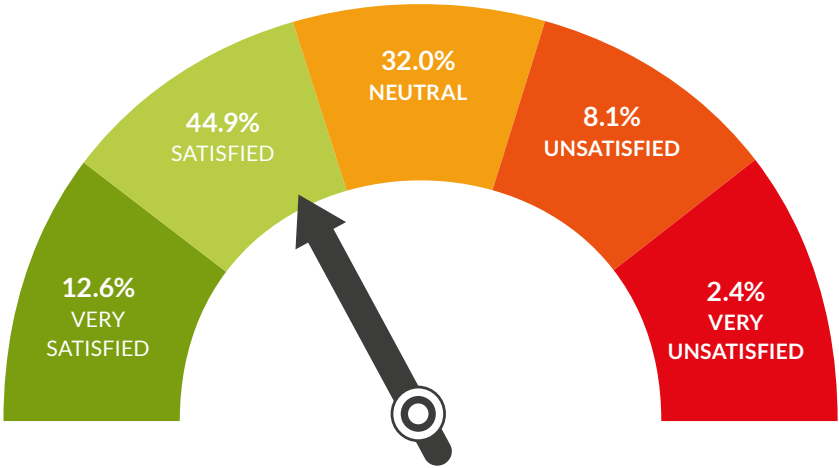


FIGURE 43. Satisfaction with level of involvement in decisions (n=247).

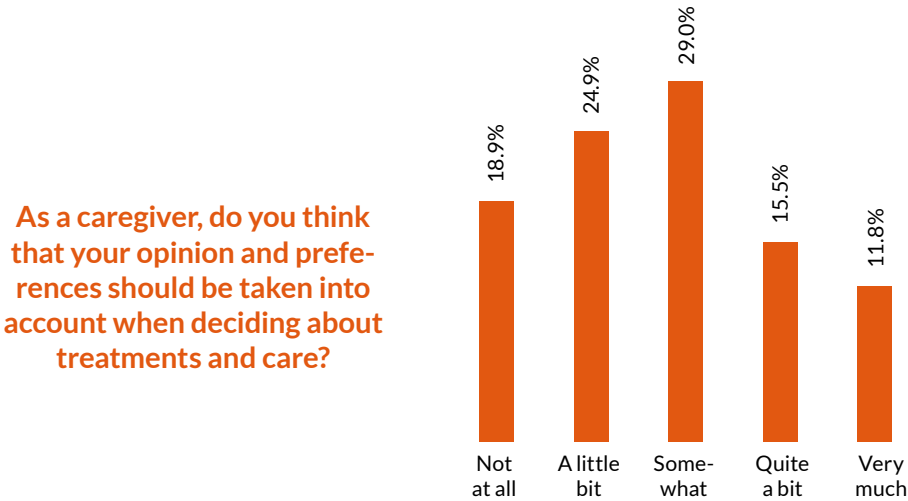


FIGURE 44. Caregiver preferences in treatment decisions (n=245).

5.4. QUALITY OF LIFE AND WELL-BEING.

Almost half of caregivers (46.1%) felt that their overall QoL was good or excellent (Fig. 45). This was below the 69.4% of people with lung cancer that reported good-excellent QoL. Therefore, **caregivers appear to experience the disease differently**. Literature shows how caregivers of people living with lung cancer exhibit significant distress and lower levels of QoL than the general population⁴³.

How would you rate your overall quality of life during the last past week? Select a number between 1 (very poor) and 7 (excellent) that best applies to you.

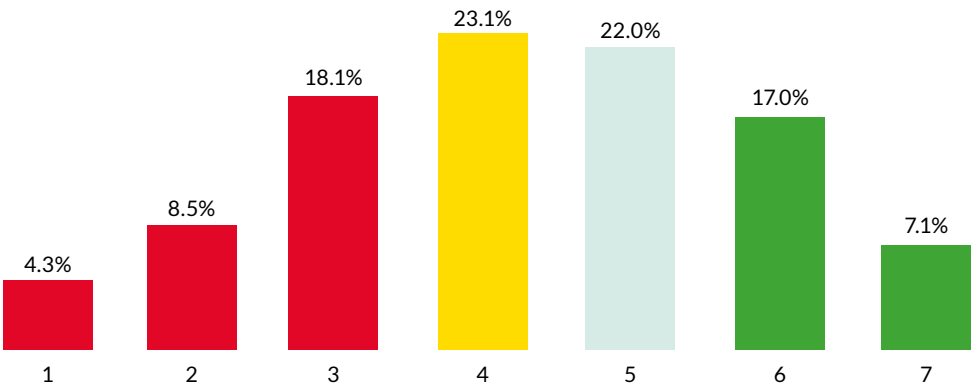


FIGURE 45. Quality of life (last week) (n=282).

Caregivers interviewed for this report confirmed that their **QoL depended on the clinical and health situation of their loved one**. Most of the respondents used first person plural when talking about how they value their own well-being, indicating that they feel their needs are intertwined with those of the person they care for.

“My quality of life is okay right now, my uncle responded to the treatment but lost one lung and lost the ability to work and he’s always tired, but he is better now and has a lot of support. His life is okay for now, so our life is okay too”.

“When my husband was alive it was around a 2. In the beginning we were more optimistic but as time went by we were devastated. There was no quality of life at all during the last moments of his life”.

“5 because we are optimist now about his condition, but it varied a lot throughout the whole process”.

“The feeling of quality of life cannot be excellent because we need to adapt ourselves to the medical presence”.

The experience of caregiving can make people sometimes neglect their own health. Some studies have found caregivers often engage in unhealthy lifestyle behaviors after their loved one's diagnosis⁴⁸.

Our survey shows a **significant group of participants (51.8%) who stated not to self-care at all or just a little bit** (Fig. 46). Only 18.9% of caregivers looked after their own health by ‘quite a bit / very much’. It seems that caregivers are mainly dealing with their loved ones needs rather than their own.

Since your loved one was diagnosed, have you looked after your own health, including eating, exercising and sleeping properly?



FIGURE 46. Self-care since the patient's diagnosis (n=270).

“I tried to deal with the problem and therefore stopped taking care of myself completely. I didn't care if I ate, I forgot about my kids, I completely neglected myself and my whole life. I decided to be committed to him and to the whole process. I knew what I was fighting for, so there was no time for me to deal with myself”.

Women reported much less self-care than men in our survey: 20.4% of women (45/220) have not looked after their own health at all (16 points over men: 2/50) and 16.0% have done it *‘quite a bit / very much’* (35/220), while this percentage was 32.0% among men (16/50).

More than half of caregivers (53.7%) had reduced their physical activity.

This was primarily due to their emotional situation (59.5%), fatigue (53.2%), caregiving responsibilities (40.2%) and their loved one’s emotional situation (38.7%). Physical activity reduction was reported more frequently by women (57.0%) than men (38.8%).

Have you reduced or increased your physical activity levels after your loved one’s diagnosis?

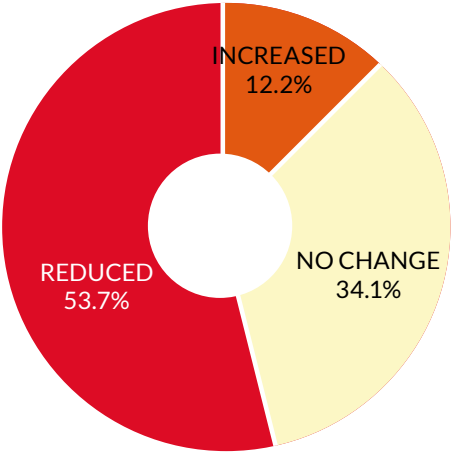


FIGURE 47. Impact on physical activity levels (n=270).

Have you ever experienced the following difficulties to physical exercise since diagnosis?

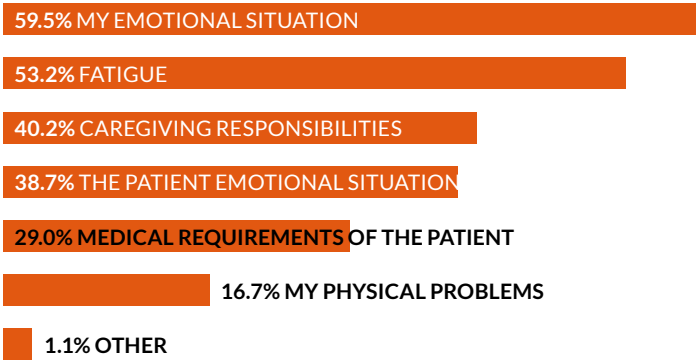


FIGURE 48. Difficulties to physical exercise (n=269).

Nutrition has also been negatively affected, according to 46.6% of respondents (Fig. 49).

The main reasons reported by caregivers were that their eating patterns had changed because of stress (67.6%) and that their nutrition had become a secondary concern (59.8%) (Fig. 50).

Our findings suggest that health promotion interventions focused on diet, exercise and resting time should be offered to caregivers.

Has the caregiving affected your nutrition?

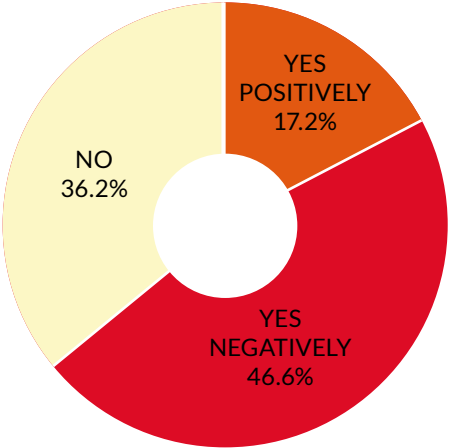


FIGURE 49. Impact on physical activity levels (n=270).

Have you experienced any of the following meal-related behaviors?

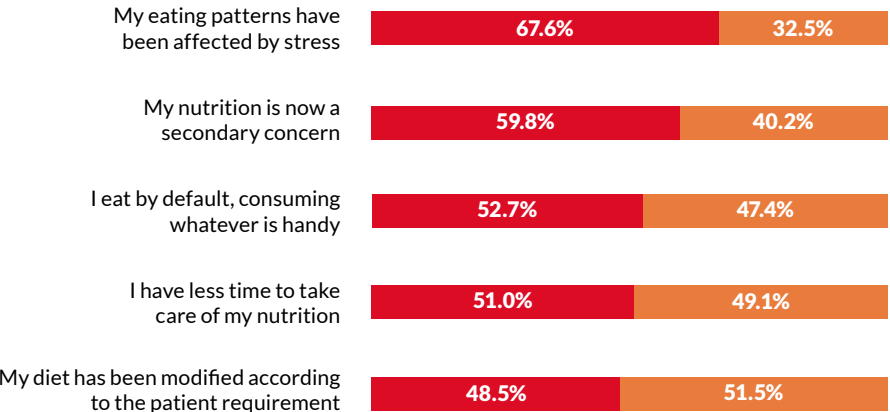


FIGURE 50. Meal-related behaviors (n=269).

Almost all participants reported to have experienced **sleep disturbances**. This was the most frequent and severe physical need according to respondents (see Figure 33: *Physical problems since caregiving*). The **main reasons reported were worries and concerning thoughts** (82.2%), followed by issues related to **their loved one's discomfort** (41.9%).

What are the reasons that have interfered the most with your sleep pattern?

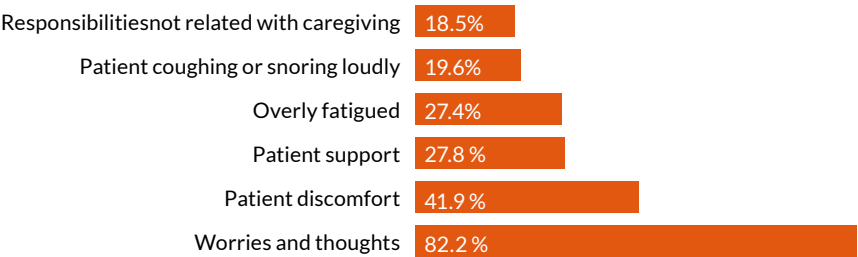


FIGURE 51. Reasons that interfered in sleep pattern (n=270).



“I’m a guy who used to exercise everyday but when my brother was diagnosed, I had no time for myself and therefore I stopped. I started having headaches and backaches that I had to ignore in order to take care of him”.

“The constant lack of time reflected in irregular meals and too little sleep”.

“I do less physical exercise now, but not because of her, but because I don’t feel like it”.

Personal interaction with the person living with lung cancer and social life are important variables. Following diagnosis, more than half of the participants (56.9%) felt that they had a closer relationship with the person with lung cancer. Only a few (5.9%) reported a more distant relationship (Fig. 52).

This is consistent with caregivers' interviews responses. All of those interviewed confirmed that their relationship had changed because of the disease experience, and 5 out of 8 specifically pointed out how their relationship had become more intimate than before diagnosis.

Do you feel that your relationship with the person with lung cancer has changed?

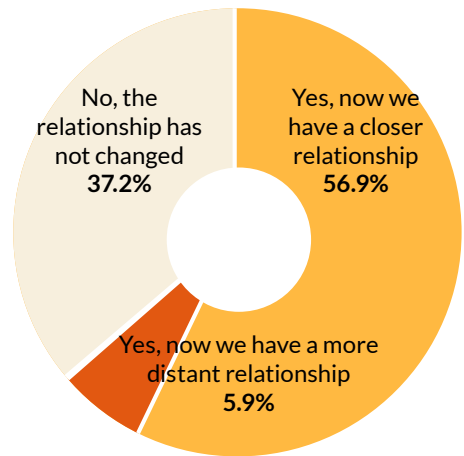


FIGURE 52. Changes on relationship with the patient (n=253).

“I’m definitely closer to my uncle and my other family members than I was before the diagnosis”.

“My relationship with her on a physical level has changed, but it has still brought us closer together as a couple”.

“For the past few months he has been much better. It’s impossible not to be nervous but it has brought us all closer to each other”.

Almost half of participants who had experienced a more distant relationship reported feelings of guilt related to the disease (46.7%) and having sleep disturbances because of the person coughing or snoring loudly (46.7%). These percentages fell to 19.6% and 18.8% in caregivers with a closer relationship.

Do you feel that your relationships with other people has changed?

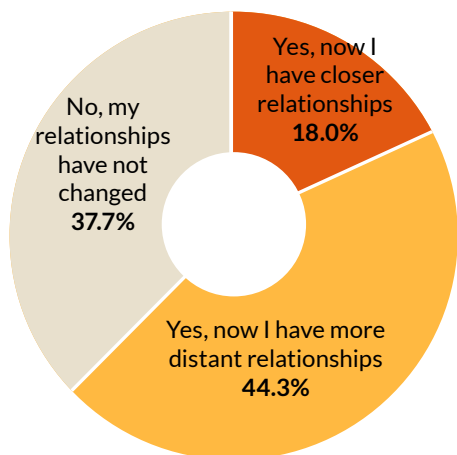


FIGURE 53. Changes on relationship with other people (n=255).

On the other hand, some participants reported a greater impact on relationships with other people: **44.3% felt they have more distant relationships since diagnosis**, and only 18.0% stated they have closer relationships with other people (Fig. 53).

In our previous report (2020)²⁴, we asked specific questions relating to relationships with friends and the percentages observed were pretty similar to our current findings: 38.6% reported feeling distanced from some friends following diagnosis.

5.5. END-OF-LIFE DECISIONS AND CARE.

The last set of questions were related to end-of-life decisions and care. 198 participants completed this section of the survey. Among them, 35.9% were caregivers of someone who had passed away.

a) Experience of people whose loved one had passed away.

Most stated they had discussed end-of-life care with their loved one (59.4%), however half the respondents recognised that it was not enough (Table 10). If we add the 11.6% that didn't talk about this and would have liked to, we find that **40.6% were not satisfied with the discussions they had with their loved one about end-of-life decisions**. This percentage is similar to data from people diagnosed with lung cancer: 44.2% of them would have liked to have had a more in-depth discussion.

On the other hand, **68.1% acknowledged to having shared their feelings** with their support network. However, half of them again reported that this level of sharing was not enough.

| | Yes | Yes, but not enough | No, but I would have liked to | No, because there was no need | No, I preferred not to |
|--|-------|---------------------|-------------------------------|-------------------------------|------------------------|
| Did you ever share your feelings within your support network? (n=69) | 33.3% | 34.8% | 7.3% | 2.9% | 21.7% |
| Did you ever discuss end-of-life care with your loved one? (n=69) | 30.4% | 29.0% | 11.6% | 8.7% | 20.3% |

TABLE 10. Communication regarding end-of-life.

Support for people impacted by lung cancer is essential at the end-of-life stage. It is a very stressful time for people diagnosed with the disease and their caregivers. According to people who have already experienced these difficult times, the main difficulties they experienced supporting their loved one related to symptom management (77.9%), emotional support (76.5%), how to offer best care (76.5%) and patient comfort and dignity (73.5%) (Fig. 54).

“No one told us about a lot of things we could have been prepared for as a family, such as certain side effects of the medicine for example. It made us feel useless, incapable to react”.

As a caregiver, what were the main difficulties you had supporting your loved one at the end of life?

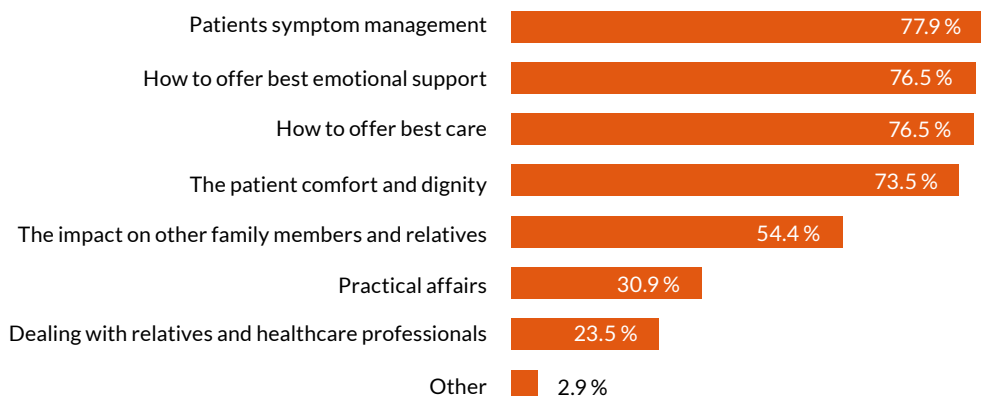


FIGURE 54. Support difficulties at the end-of-life (n=68).

How do you value the support that you (patient and caregivers) received during the last days of life?

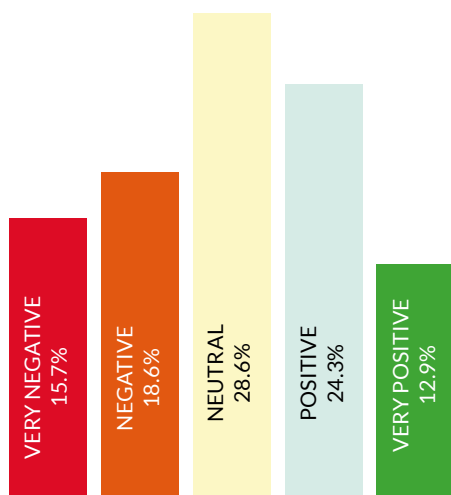


FIGURE 55. Satisfaction of support received at the end-of-life (n=70).

The experiences of those who have cared for someone who had passed away were varied and diverse. Some valued the support in a positive way (37.2%) and others more negatively (34.3%) (Fig. 55). There may be many reasons for this disparity. We believe that access to palliative care has a great influence on end-of-life care perceptions with wide differences experienced across Europe⁴⁹.

It is an important priority to highlight the requirement of access to end-of-life supportive care. Additionally, a holistic approach to care, addressing the physical, psychosocial and spiritual needs of people at all stages during the care journey should be available.

b) Experience of people whose loved one is alive.

Half of participants (50.0%) have discussed end-of-life with their loved one. However, half considered that they had not discussed it enough, and we identified a further 9.5% who had not talked about end of life even though they would have liked to (Table 11).

31.8% of respondents have not had this discussion because they preferred not to, even when they realised it was required. Clearly, talking about end-of-life remains a taboo and it is frequently avoided by many.

A third of participants (33.4%) shared their feelings with their support network. There is a clear need to promote these types of conversations: **34.2% would like to talk about their feelings to a greater extent.**

| | Yes | Yes, but not enough | No, but I would have liked to | No, because there was no need | No, I preferred not to |
|---|-------|---------------------|-------------------------------|-------------------------------|------------------------|
| Have you ever shared your feelings about end-of-life of your loved one within your support network? (n=126) | 18.3% | 15.1% | 19.1% | 18.3% | 29.4% |
| Have you ever discussed with the patient about end-of-life? (n=126) | 27.8% | 22.2% | 9.5% | 8.7% | 31.8% |

TABLE 11. Communication regarding end-of-life.

The support services in higher demand by participants regarding end-of-life care involve their loved one's comfort and dignity (85.7%), symptom management (86.3%), how to offer emotional support (81.0%) and best care (75.4%) (Fig. 56).

What practical supports do you think would help you the most when deciding on end-of-life care?

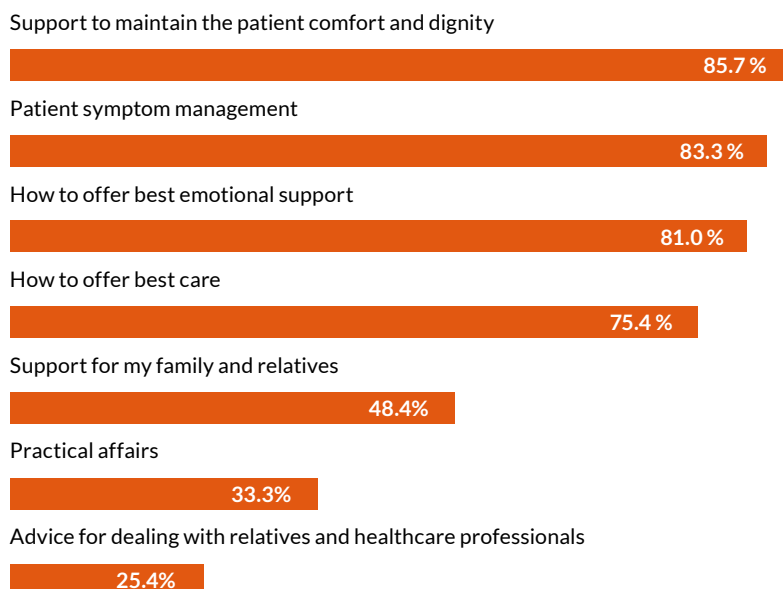


FIGURE 56. Supports preferences when deciding on end-of-life care (n=126).

“

“We have not yet broached this subject with my mother, but we do know that in the end what she wants is to be as well attended as possible. We want her to have the best possible quality of life possible, to suffer as little as possible, for her to be treated by a good palliative care unit, for all this to flow in a natural way.

Regarding this issue, perhaps we should ask the patient about this in the earlier stages, and not wait until the final moments when the patient does not have the strength to talk about it”.



“

“The home health care during the last days was excellent. It comforted us a lot, and my daughters and I are very, very grateful for the palliative medical services received by the woman with whom I had the luxury of sharing my life”.

6. Call to action

Ensure access to supports to help with the impact of lung cancer and treatment.

Systematic clinical assessment can provide a means of assessing lack of access, misconceptions and facilitate an understanding of the wide spectrum of supportive care needs for people impacted by lung cancer.

Develop care plans and educational programmes with the aim to improve quality of life for people impacted by lung cancer.

These plans must include access to multidisciplinary healthcare teams at diagnosis and throughout the care pathway. These teams should routinely assess symptom-related interference in daily life aspects, in order to develop individualised interventions that improve QoL for people living with lung cancer and those in a caregiving capacity. Caregiver specific supports should include assistance about how to care for their loved one and how to take care of their own physical and psychological health.

Develop better communication between people impacted by lung cancer and healthcare professionals.

Develop new communication modules to educate university students (e.g., medical and nursing) on the importance of better communication between people impacted by lung cancer, those in a caregiving capacity and health care professionals. These modules should also be implemented in healthcare centers.

Raise awareness and develop communication support concerning end-of-life care.

Healthcare teams should develop and put in place a communication strategy to encourage and support discussions with people impacted by lung cancer to help explore their wishes and expectations concerning end of life care. This educational programme should cover end-of-life care discussions and shared decision making.

Alone
WE CAN DO SO
— LITTLE —
TOGETHER
WE CAN DO SO
Much

7. Acknowledgements

More than 300,000 people are diagnosed with lung cancer every year in Europe. The diagnosis is the beginning of a difficult journey for which no one is prepared. However, people with lung cancer are not alone. Their loved ones accompany them in every step of their journey. Caregiving is an act of love, but we should remind ourselves that caregivers need support to deal with the challenges they face every day.

People living with lung cancer and caregivers alike, inspire us to continue working and advocating for fair policies and access to high-quality healthcare for everyone. Gathering experiences and insights is crucial to our work as advocates. Thus, we want to **thank the 800 people who completed our survey**. We really appreciate your time and hope that this report reflects your experiences as accurately as possible.

Thank you to the people who participated in the interviews for this report. Sixteen people shared important moments of their experiences living with lung cancer. Thank you so much for your time and generosity.

Our thanks to the organisations that continue to provide support, commitment and collaboration with LuCE to improve the lives for the many people impacted by lung cancer: **Amgen, AstraZeneca, Bayer, Blueprint Medicines, Boehringer Ingelheim, Bristol-Myers Squibb, Daiichi Sankyo, Lilly, Merck, MSD, Novartis, Pfizer, Regeneron, Roche, Sanofi and Takeda.**

Thank you to **MÁS QUE IDEAS Foundation** for their continued support. This report would not have been possible without the key role they played in bringing this to fruition.

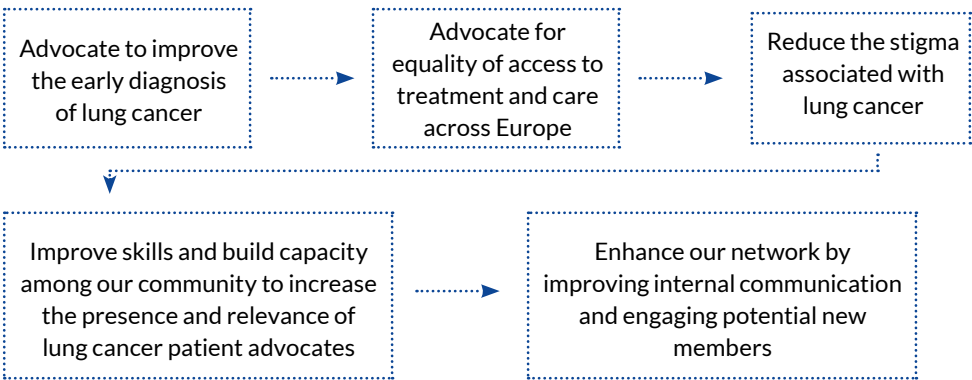
Lastly, we want to give a special thank you to **our members**, for their great support and involvement in this project. Our member organisations do a fantastic job nationwide, supporting people 365 days a year. We are very grateful that they recognise the value of working together at the European level to face challenges that we all share.

We want to specially thank to the members of the **LuCE Report Working Group** for their great support: Alina Comanescu, Bernard Gaspar, Merel Hennink, Leslie Manot and Shani Shilo. These collaborative work efforts bring true meaning to the phrase **‘Alone we can do so little, together we can do so much’**.

8. Lung Cancer Europe (LuCE)

LuCE is the voice of people impacted by lung cancer, striving to make lung cancer an EU health priority, and supporting its' members to be effective and sustainable organisations. LuCE provides a European platform for already existing lung cancer patient advocacy groups and supports the establishment of national lung cancer patient groups in different European countries where such groups do not yet exist.

LuCE activities fall under three specific pillars, **Education**, **Awareness** and **Advocacy**, and our strategic objectives revolve around them:



Meet our team:



Anne-Marie Baird
(Ireland)
President



Ewelina Szymtke
(Poland)
Vice-President



Korina Pateli-Bell
(Greece)
Treasurer



Marjo Forsbloom
(Finland)
Board member



Lavinia Magee
(UK)
Board member



Alfonso Aguarón
(Spain)
Project Manager



Charles Bisailon
(Switzerland)
Communications
Manager



Maeve O'Sullivan
(Ireland)
Executive Officer

ABOUT OUR MEMBERS

LuCE provides a platform for organisations and individuals working for people impacted by lung cancer. As of November 2021, there are 15 full members, 14 associate members and 5 individual members, representing 22 countries. We encourage you to learn more and support LuCE and our member organisations.

<https://www.lungcancereurope.eu/about-luce/member-organisations/>

FULL MEMBERS



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Lungekræft

Patientforeningen Lungekræft
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Women Against Lung Cancer in Europe
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Israel Lung Cancer Foundation
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Lung Cancer Nursing UK
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Pembe Hanım
www.pembehanim.com.tr

INDIVIDUAL MEMBERS



Regine Deniel Ihlen



Anne-Marie Baird



Tommy Björk



Nicoleta Mitrea



Ewelina Szmytko

9. Annex I. Detailed breakdown of participant characteristics

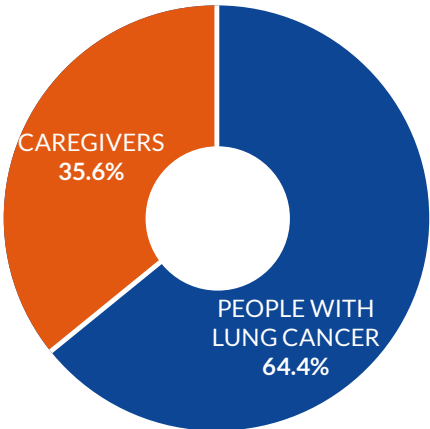


FIGURE 57. Type of participant.
515 people with lung cancer + 285 caregivers.

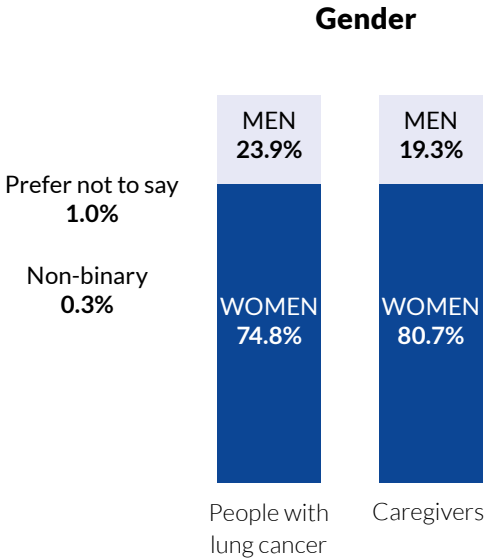
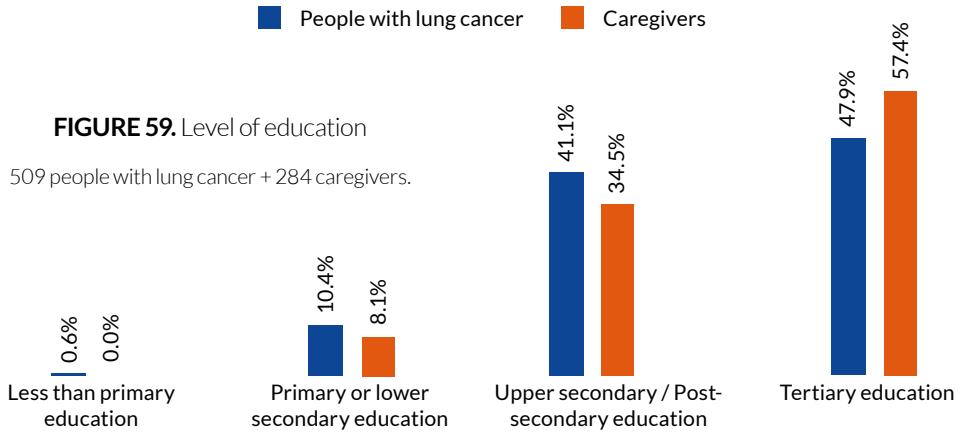
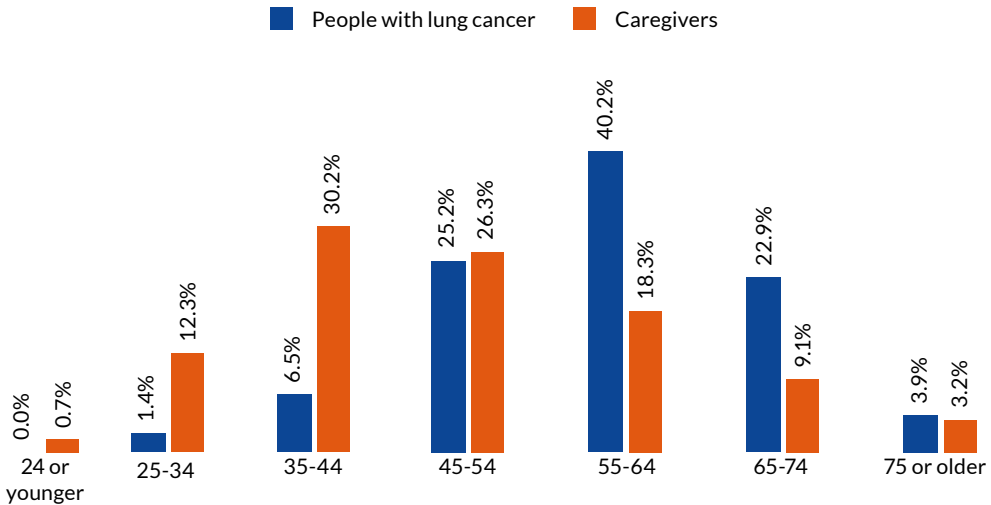


FIGURE 58. Gender
• People with lung cancer:
385 women + 123 men.
• Caregivers: 230 women
+ 55 men.

Level of education



Age



| Country of residence | Total | | Patients | Caregivers |
|----------------------|------------|----------------|------------|------------|
| The Netherlands | 146 | 18.3% | 91 | 55 |
| Greece | 107 | 13.4% | 42 | 65 |
| Spain | 95 | 11.9% | 57 | 38 |
| Italy | 73 | 9.2% | 53 | 20 |
| France | 70 | 8.8% | 57 | 13 |
| Germany | 57 | 7.2% | 47 | 10 |
| Sweden | 42 | 5.3% | 41 | 1 |
| Finland | 41 | 5.1% | 28 | 13 |
| The United Kingdom | 40 | 5.0% | 31 | 9 |
| Slovenia | 29 | 3.6% | 12 | 17 |
| Romania | 26 | 3.3% | 6 | 20 |
| Israel | 15 | 1.9% | 9 | 6 |
| Belgium | 12 | 1.5% | 8 | 4 |
| Denmark | 11 | 1.4% | 11 | 0 |
| Poland | 11 | 1.4% | 4 | 7 |
| Norway | 6 | 0.8% | 4 | 2 |
| Ireland | 5 | 0.6% | 4 | 1 |
| Latvia | 5 | 0.6% | 3 | 2 |
| Austria | 3 | 0.4% | 2 | 1 |
| Switzerland | 2 | 0.3% | 2 | 0 |
| Hungary | 1 | 0.1% | 0 | 1 |
| Total | 797 | 100.00% | 512 | 285 |
| Missing | 3 | - | 3 | 0 |

TABLE 12. Table 12. Country of residence.

People with lung cancer: specific characteristics

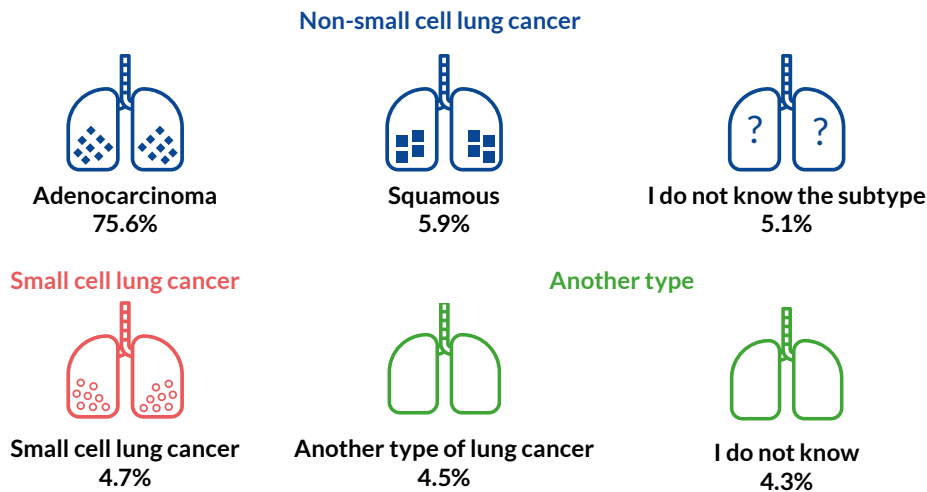


TABLE 13. Type of lung cancer (513 participants).

Is your tumour positive for any of the following markers?

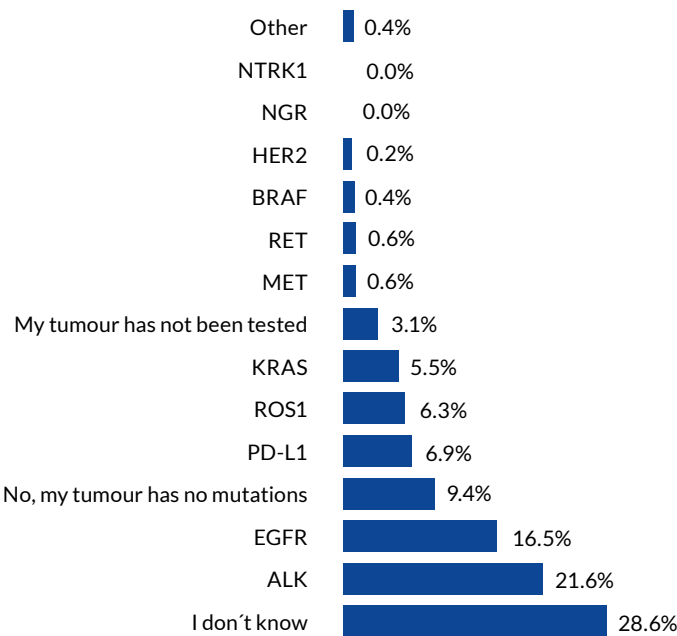


FIGURE 61. Tumour positive marker (510 participants).

Which defines your current clinical situation?

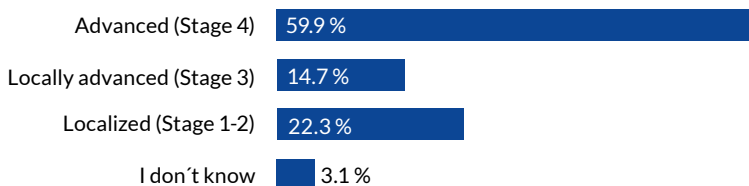


FIGURE 62. Stage of disease (511 participants).

If your cancer has spread, where has it spread to?

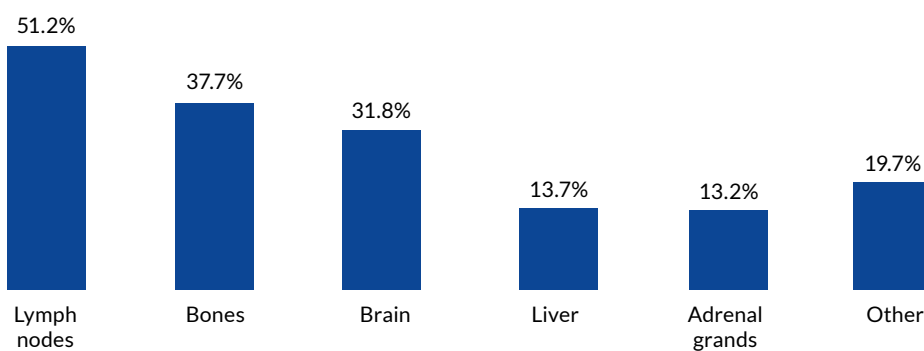


FIGURE 63. Metastasis localization (489 participants).

People who care for someone with lung cancer: specific characteristics

The person diagnosed with lung cancer is...

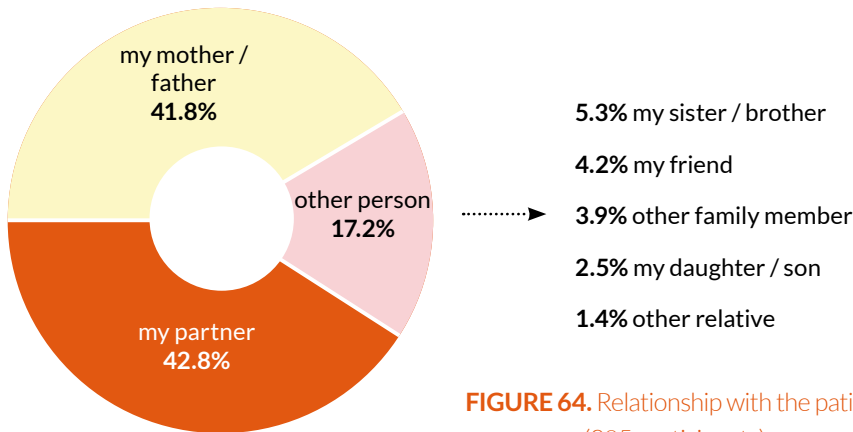


FIGURE 64. Relationship with the patient (285 participants).

Are you the primary caregiver?

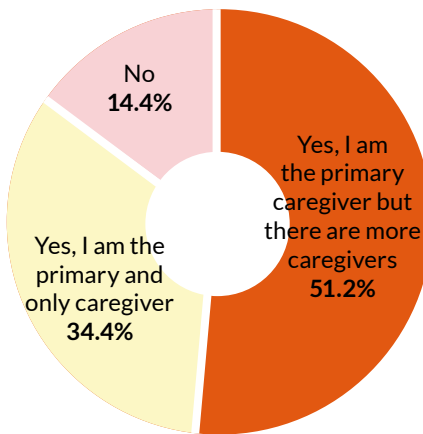
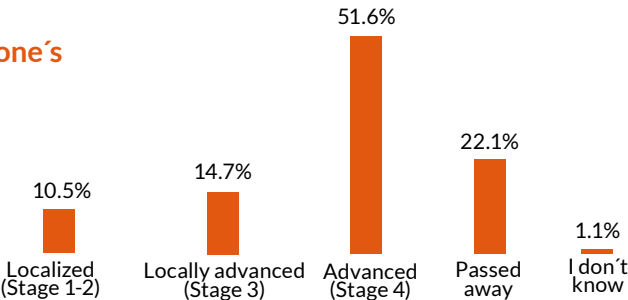


FIGURE 65. Primary vs. non-primary caregiver (285 participants)

Which defines your loved one's current clinical situation?

FIGURE 66. Current situation of patient (285 participants).



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