CANCER SUPPORT COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

GILDA'S CLUB

How NSCLC Affects Quality of Life

Findings from a recent Cancer Support Community study

ABOUT NSCLC AND THIS STUDY

Lung cancer is the third most common cancer in the United States. About 8 out of 10 people with lung cancer have non-small cell lung cancer (NSCLC). NSCLC can place a heavy burden on patients, with ongoing challenges that affect quality of life.

Cancer Support Community (CSC) recently conducted a study to understand how NSCLC affects quality of life, including the role of different types of treatment, symptoms, and disease stage.

HOW THE STUDY WAS DONE

We analyzed 279 responses to the Cancer Experience Registry (CER) and conducted interviews with 25 people receiving different types of treatment for NSCLC.

Participants were asked about:

- their emotional and physical well-being,
- treatment experiences,
- how symptoms impact daily life, and
- unmet support needs

KEY TAKEAWAY

People diagnosed with NSCLC need customized support to help make informed decisions around treatment, deal with symptoms, and manage distress.

WHAT WE FOUND

Anxiety and Fatigue Were Common: Anxiety (**84%**) and fatigue (**60%**) were among the most frequently reported challenges and negatively affected quality of life. Participants described the highest levels of anxiety at diagnosis and treatment start due to limited information about the disease and potential side effects.

Fear of Recurrence Was a Major Concern: Worry about cancer returning or progressing was the most common source of anxiety. Participants frequently expressed a need for more information to feel informed and supported in their decisions.

Experiences Differed by Disease Stage: Participants with metastatic and non-metastatic NSCLC described different experiences. Those with non-metastatic disease reported greater anxiety about recurrence and greater limitations in quality of life, while unmet needs were similar across both groups.

Clear Information Matters: Most participants (**84%**) reported needing clearer, easier-to-understand information about NSCLC, treatment options, side effects, and what to expect throughout their care.

Side Effects Can Affect Daily Life: Nearly all participants (**96%**) experienced treatment-related symptoms, and many reported that side effects affected their ability to work, travel, socialize, and complete everyday activities.

Pain Can Continue After Surgery: More than two-thirds of participants (**68%**) reported pain during treatment. Among those who underwent surgery, many reported pain that affected sleep, mobility, and daily activities for months after treatment.

Confidence Grew Over Time: As participants learned more about their disease and treatment options, they felt more informed and more involved in decisions about their care.

HOW CSC CAN HELP

CSC offers a range of resources and programs to support people affected by cancer. Below are some that are particularly relevant to what we found in this study. For more, visit **cancersupportcommunity.org**

Get Support

Living with NSCLC can bring emotional challenges at every stage. The Cancer Support Helpline connects you with trained specialists who can provide emotional support, resources, and guidance tailored to your needs. Call 888-793-9355 (available in more than 200 languages)

Manage Fatigue

Fatigue was one of the most common challenges reported by participants and often affected daily life. Check out CSC's article on managing cancer-related fatigue for practical strategies and tips to help conserve energy and improve quality of life. **cancersupportcommunity.org/article/fatigue**

Support Your Mental Health

Anxiety and emotional distress were common among participants with NSCLC. CSC released a Mental Health and Cancer factsheet about coping strategies and support resources that can help you navigate the emotional impact of cancer. **cancersupportcommunity.org/mental-health-factsheet**

Cope with Fear of Recurrence

Worry about cancer returning or progressing was the most commonly reported source of anxiety in this study. CSC's article on managing fear of recurrence can help you find strategies to cope with uncertainty and regain a sense of control. **cancersupportcommunity.org/article/managing-fear**

Connect with Others

Many participants expressed a desire to connect with others who understand what they are going through. Join CSC's MyLifeLine online community to connect with family, friends, caregivers, and others impacted by cancer. **mylifeline.org**

Find Local Services

Connecting with others who understand your experience can help reduce feelings of isolation and distress. Find free support groups, educational programs, and wellness services available through CSC locations across the country. **cancersupportcommunity.org/find-location**

Prepare for Medical Appointments

Many participants reported wanting more information and support when making treatment decisions. CSC's Open to Options program can help you create a personalized list of questions and concerns so you feel more informed and prepared for medical appointments. 888-793-9355 or contact your local CSC or Gilda's Club

Learn About NSCLC

Understanding your diagnosis, treatment options, and what to expect can help you make informed decisions about your care. Visit CSC's NSCLC resource center for educational information and support resources. **cancersupportcommunity.org/non-small-cell-lung-cancer**

Understand Your Treatment Options

Check out CSC's "Which Biomarkers Matter for You and Why?" interactive tool to learn how biomarker testing can help you and your care team identify treatment options that may be right for you. **cancersupportcommunity.org/biomarker-testing-tool**

Share Your Experience

Your experience matters. If you are living with NSCLC and are interested in sharing your perspective, we invite you to participate in the Cancer Experience Registry. For more info please contact us at registry@cancersupportcommunity.org

This summary describes findings from a study conducted by the Cancer Support Community in collaboration with Gilead Sciences. This study was funded by Gilead Sciences.

CANCER SUPPORT COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

GILDA'S CLUB