



Image is not of actual patients.

## A HELPING HAND: Advice on Caring for Someone With Non-Small Cell Lung Cancer From Those Who Do It

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### Contents

- 3 Think Broadly
- 5 NSCLC
- 5 Exon 20 Insertion Mutations
- 5-7 Biomarker Testing
- 7 Lung Cancer Specialist
- 8 Financial Assistance
- 8 Keeping Records
- 8-9 Emotional Needs
- 10-11 Patient Advocacy
- 12 Clinical Trials
- 12 Moving Forward
- 16 Survey Objectives
- 16 Survey Methodology
- 17-22 Survey Details
- 23-24 Acknowledgments
- 25 Glossary
- 26-27 References

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Cancer affects not only the person with the diagnosis but those around them, particularly care partners. As a care partner for someone diagnosed with non-small cell lung cancer (NSCLC), you may wonder how best to provide support for them. You may have questions about treatments and side effects or wonder how best to support their needs, both today and in the future.

“It’s a lot of pressure for everyone,” said Carter, whose wife was diagnosed with NSCLC in 2021.

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Carter is one of 35 people who took part in a survey sponsored by Takeda in the summer of 2021. They all volunteered to share their experiences as a care partner for someone living with NSCLC. (We’ve changed their names to protect their privacy.) This article is a collection of their thoughts, feelings, and insights. It is, in essence, what they wished they had known when they first started caring for someone with NSCLC.

#### SURVEY PARTICIPANTS

- Most respondents were:  
Caring for someone age 40 or up
- Female
- Non-Hispanic, White/Caucasian, or Euro-American
- Living in either an urban or suburban setting, as opposed to a rural environment

According to a joint study by the American Association of Retired Persons and the National Alliance for Caregiving, more than 53 million people in the US acted as a care partner to someone living with cancer in 2020.<sup>1</sup> While much of a caregiver’s work likely goes unseen, it has both merit and worth. In 2017, the estimated economic value of the unpaid contribution of care partners for adults was approximately \$470 billion.<sup>2</sup> It’s the kind of work that is both physically and emotionally draining. Yet it is also something that can pull people together in poignant moments, strengthening the bonds between them.

The role of care partner falls on many unexpectedly, just like NSCLC. This year, an estimated 235,760 people in the US will be diagnosed with the disease. It is, in fact, the most common type of lung cancer.<sup>3</sup>



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Having lung cancer today is quite a bit different than it was even 10 years ago. Advancements in science have uncovered several different types of NSCLC. The care partners who took part in this survey were caring for someone who was diagnosed with epidermal growth factor receptor (EGFR) Exon 20 insertion mutation.

### Think broadly about your care and assistance from the community

In this survey, most care partners were, like Carter, the spouse of the patient. However, approximately 43% were not. They were parents, children, siblings, friends, and nieces. It’s important to know that care partner relationships vary.

#### What is your relationship to the individual diagnosed with non-small cell lung cancer (NSCLC) with the EGFR Exon 20 insertion mutation for whom you provide care and/or support?

Spouse	57.1%
Adult child	28.6%
Other (Responses included father, brother, niece, and daughter.)	11.4%
Friend	2.9%

Carter took on the role of care partner alone. Yet, he still works at the same job he had before his wife was diagnosed. He has, however, had to adjust his work schedule to provide care and support. He helps his wife get to appointments at her specialty hospital, reads about the latest advancements and treatments, finds support groups, and brings in questions for the healthcare team to ensure he is prepared for appointments and they are productive. He also provides emotional support when things get rough and helps with daily activities. This kind of busy schedule was typical of the people who responded to the survey. In fact, everyone who responded was supporting their loved one in many of the areas noted in this publication.

Making decisions with an oncologist regarding treatment plans is critical. The majority of care partners said they became more involved in decision-making as time went on. However, only 17% of care partners surveyed said they played a key role in deciding what the best treatment would be. It’s important to note that patients may not want their caregivers involved in these decisions. The decision-making dynamic between you and your loved one may evolve over time. Early on and throughout this journey, take time to discuss what your loved one wants and needs.



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**What is the care and/or support that you provide for the individual with non-small cell lung cancer (NSCLC) with the EGFR Exon 20 insertion mutation? (please indicate all relevant services)**

Emotional support	94.3%
Responsibility for sharing health updates with family and friends	85.7%
Questions and discussions with the doctor and care team	82.9%
Research into NSCLC and treatments	77.1%
Transportation to/from visits to the doctor, for laboratory tests, scans, and/or treatments	57.1%
Interacting with advocacy groups and interacting with social media groups run by patient advocacy groups	57.1%
Aid in daily needs such as shopping and preparation of meals	54.3%
Management of side effects from treatment	51.4%
Additional responsibilities for childcare	20.0%
Other	2.9%

With so many ways to help, creating a community of care partners who each take on different roles might work best in your situation.

Helen was initially the sole care partner for her husband, who was diagnosed with NSCLC in 2014. "As the disease progressed, I needed outside hired help," she said.

Consider the opportunities and skills of those around you.

Min, whose husband was diagnosed with NSCLC in 2020, found a great addition to her care team by looking just a little further afield. "My daughter's boyfriend who is a scientist was able to translate medical articles to layman's terms and help me chart all the treatments he had and the scan results as well as the treatment possibilities," Min said.



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People often want to help but simply don't know what to do, so you'll want to be very clear about what's involved and check in regularly. See the resource list in this document for sites that help you keep everyone on track. Be aware that you might have to start off with the basics of lung cancer, which might mean brushing up on those yourself.

Carter dove right into the research. (Most, though not all, of the care partners surveyed found that doing their own research was helpful.) In fact, like the majority of those surveyed, Carter said he started researching the disease immediately after getting his wife's diagnosis.

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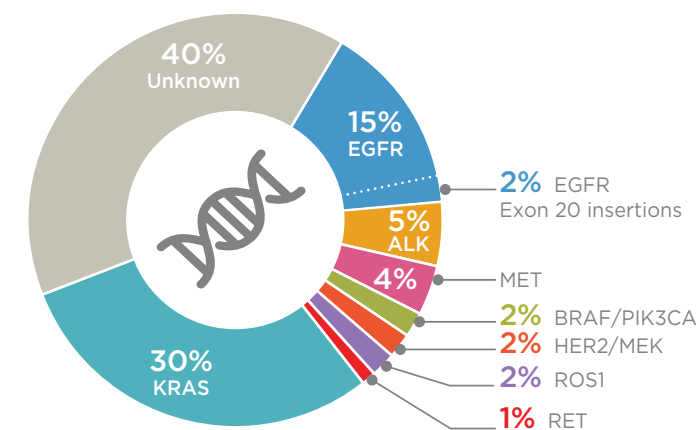
**NSCLC: A cancer with many possible paths**

In the US, NSCLC often involves tumor cells called adenocarcinomas. These cells, which grow out of control, are found in the lining of the lungs.<sup>4</sup> But the illness can spread, or metastasize, to other areas of the body, such as the bones, liver, brain, lymph nodes, or adrenal glands.<sup>5</sup> That's why, for some patients, the first signs don't feel like what you'd expect from lung cancer.

That's how it was for Lucas' wife, who was diagnosed in 2020 after the disease had crept into her shoulder. They went for an MRI and tissue biopsy of her shoulder, only to be told she had NSCLC. "Brace yourself. It's a roller coaster," he said.

Like all lung cancers, NSCLCs happen because of mutations, or mistakes, that develop in genes<sup>6</sup> with unwieldy names, such as epidermal growth factor receptor (*EGFR*), anaplastic lymphoma kinase (*ALK*), and c-ros oncogene 1 (*ROS1*).<sup>7</sup> The mutation responsible for the cancer is sometimes referred to as the driver mutation.<sup>8</sup> Finding out which change—or biomarker—is responsible for the growth of your lung cancer is recommended by leading medical and advocacy organizations, such as the American Cancer Society<sup>9</sup> and LUNGevity.org,<sup>10</sup> because the information can affect decisions about care. The test involves a tissue sample or blood draw to investigate possible mutations.<sup>11</sup>

**Driver mutations in NSCLC adenocarcinomas<sup>12-14</sup>**



For some NSCLC patients, the answer is found on a gene called EGFR. This gene has the instructions for making a protein with the same name.<sup>15</sup> But there's more than one way this gene can mutate, and finding out what type of EGFR mutation is responsible for your loved one's NSCLC can make a big difference in finding the ideal treatment.<sup>16</sup>

**Exon 20 insertion mutations: A rare and emerging priority**

One kind of EGFR mutation that can lead to NSCLC is known as the Exon 20 insertion mutation. They are called insertion mutations because they involve extra bits of DNA inserted into the gene, much like an extra word in a sentence that changes its meaning.<sup>16,17</sup> Exon 20 insertion mutations only occur in approximately 2% of patients with an NSCLC diagnosis and approximately 10% of all cancers with a documented EGFR mutation, making them rare.<sup>12-14</sup>

NSCLC patients with an Exon 20 insertion mutation usually had a tougher time with the disease than those with other EGFR mutations.<sup>14,18,19</sup> The Exon 20 insertion mutation changes the shape of the EGFR protein in a way that makes it hard for some of the older treatments to work.<sup>14,18,19</sup> Thankfully, some treatments specifically designed for patients with Exon 20 insertion mutations are now available.<sup>20,21</sup>

**Talk to your loved one about comprehensive biomarker testing**

There are multiple ways to test for mutations, including polymerase chain reaction (PCR)<sup>22</sup> and next-generation sequencing (NGS).<sup>23</sup> This method can detect many mutations simultaneously, investigating thousands and even millions of possible mutations. It would take many traditional tests to equal the diagnostic power of just one NGS test. Consequently, opting for NGS could be easier for the person you are caring for, as the healthcare provider may not have to remove as much tissue.<sup>23</sup>

Kathleen Phan, a project manager for the clinical trials office at City of Hope Comprehensive Cancer Center in Long Beach, California, said that in her experience, "most of the time, the doctors would prefer NGS testing because it's just more comprehensive."<sup>24,25</sup>



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Marcia Horn is the Executive Director of the Exon 20 Group and the President and CEO of the International Cancer Advocacy Network. “PCR is missing a good 50% of all EGFR Exon 20 insertion mutations, which can be disastrous for a patient,” she said. “Fortunately, NGS will pick up the 50% that PCR fails to identify.”<sup>24,25</sup>

Dr. Andre Liem is a medical oncologist and hematologist who is also affiliated with City of Hope Comprehensive Cancer Center. He said he also prefers NGS biomarker testing.

“With the NGS, you’ll get the most information upfront so you don’t have to go back each time to get follow-up testing,” said Dr. Liem.



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Your loved one’s healthcare providers may not routinely offer biomarker testing. More than 17% of those surveyed said genetic testing was not recommended at their initial visits for NSCLC.

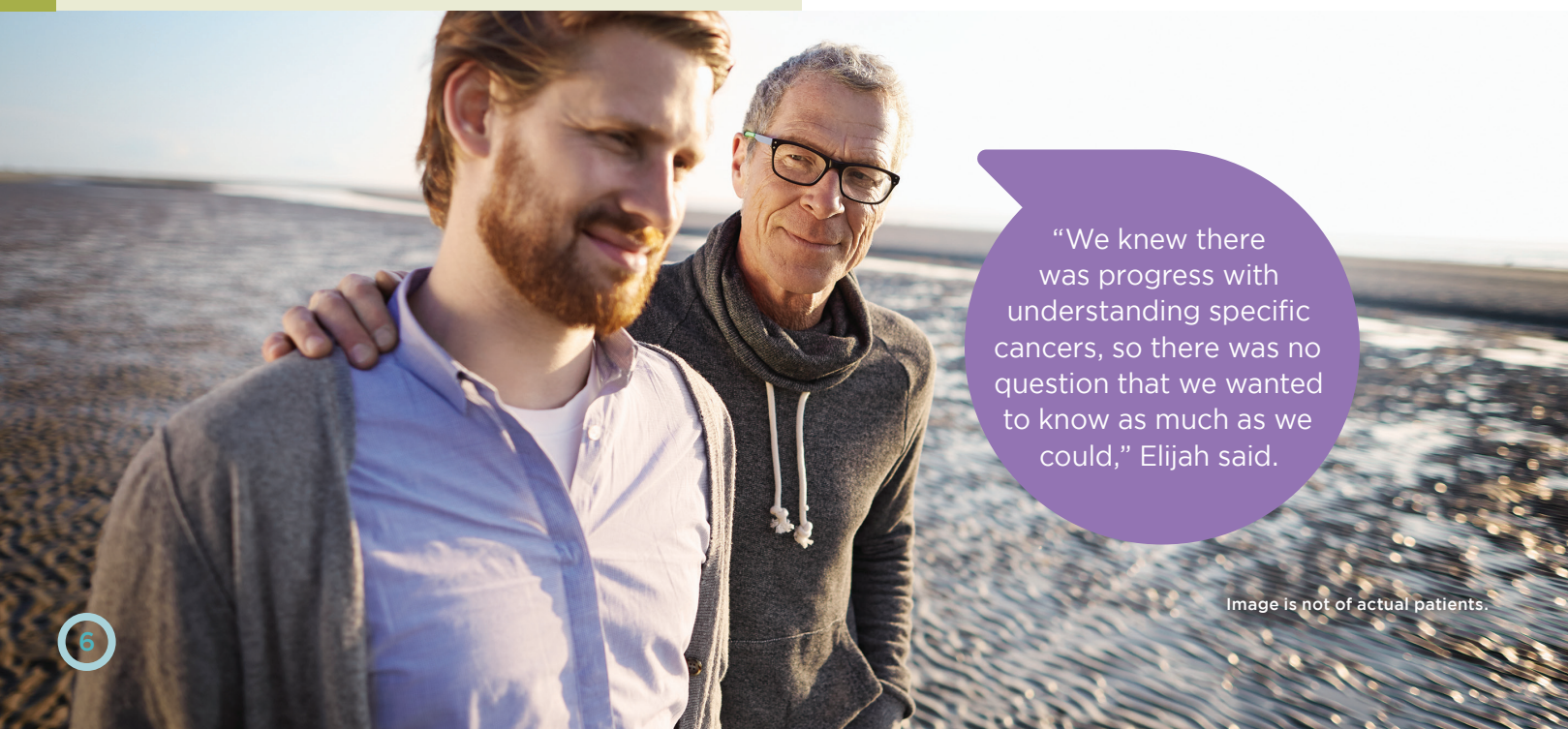
Achara, whose husband was diagnosed with NSCLC in 2019, said her doctor was “not forthcoming” about what type of EGFR mutation her husband had. Achara said she had to be quite persistent to find out it was an Exon 20 insertion mutation.



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It’s important to be proactive about testing: talk to your loved one about requesting such tests the next time they talk to someone on their medical team. More than 25% of care partners surveyed said it took more than a month after the patient was first diagnosed with NSCLC before genetic testing was recommended. Results took another week or two. So don’t wait for a healthcare practitioner to raise the issue. Without those test results, treatment may not be adequate.<sup>10,11</sup>

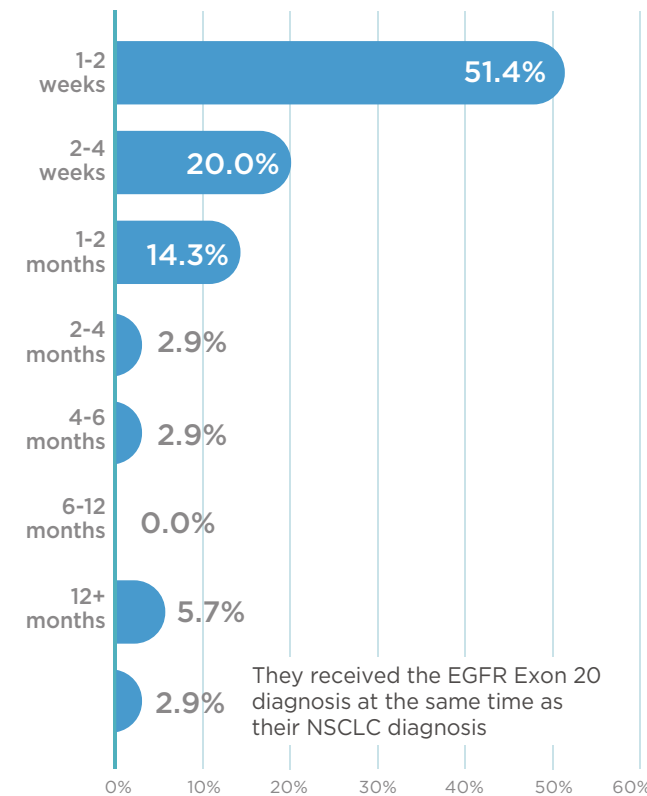
Elijah has been helping care for his son, a middle-aged man who lives in the Midwest. “We knew there was progress with understanding specific cancers, so there was no question that we wanted to know as much as we could,” Elijah said. “The information and courses of action continue to unfold. It is a dynamic process.”



“We knew there was progress with understanding specific cancers, so there was no question that we wanted to know as much as we could,” Elijah said.

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How much time passed from the time the individual for whom you provide care and/or support was first diagnosed with non-small cell lung cancer (NSCLC) and the time it was recommended that genetic mutation testing (changes in genes that may help identify the specific kind of NSCLC) should be performed? (please check one)



If the person you’re caring for already received biomarker testing but you can’t quite remember what type it was—you’re not alone. Nearly 66% of care partners surveyed weren’t sure whether their partner received PCR or NGS testing. Simply ask next time and ask if NGS testing could be done now if it wasn’t before so their results are complete.

Biomarker tests are often covered by health insurance, though this varies from one provider to the next. Some still consider such testing for NSCLC experimental, despite the fact several professional organizations have developed guidelines for biomarker testing and treatment.<sup>26</sup> Remember that this testing is important for identifying the best treatment for your loved one.<sup>11</sup>



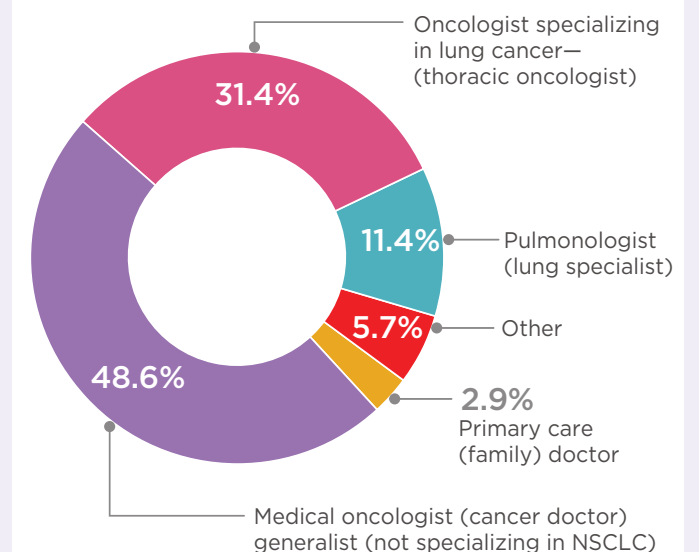
### Consider a lung cancer specialist as part of their medical team

Most of the care partners surveyed said their loved one got their diagnosis from someone who did not specialize in lung cancer, such as a primary care physician or general oncologist. Note that this doesn’t mean they didn’t later see a lung cancer specialist. In fact, such a person can be an important part of the healthcare team when treating NSCLC.

If there isn’t a lung cancer specialist near the person you’re caring for, some may be open to reviewing their case while the rest of the care is done near you. They can act as a second opinion, making sure the care is complete.

Min got a second opinion, and a third. “[We] visited 2 lung cancer specialists to decide who to go with,” she said.

### What type of doctor first diagnosed non-small cell lung cancer (NSCLC) with the EGFR Exon 20 insertion mutation in the individual for whom you provide care and/or support? (please check one)



## Explore financial assistance programs

If the person you are caring for is struggling to cover the general costs of care, know that they are not alone. Of those surveyed who said their loved one had been impacted by the disease, more than 70% noted a financial impact. For Helen and her husband, the costs of travel and accommodations when accessing care were problematic. Other costs noted by care partners included the cost for medication, lab services, travel, childcare, and income lost because either the care partner or the patient had to reduce their work schedule or responsibilities.

Andrew and his mother have been jointly caring for his father since he was diagnosed with NSCLC in 2016. They had to make some hard choices about their finances as a family. “Because of his reduced life expectancy, my father modified his retirement benefits so that they would convert to survivor benefits—with my mother as the beneficiary—after his death. Because of this change, he receives less each month now than he would have before the modification,” Andrew explained.

Your loved one may have access to a social worker or office manager who can guide them to financial resources. Ask people on the healthcare team who might be that person!

You can find details on organizations offering support with financial challenges, as well as other types of support, in the Helpful Resources and Support section of this document.

## Keep a record of what happens at appointments

Many care partners attend medical appointments. It’s important to note that while simply being there can be extremely helpful in terms of emotional support, you can also play another role while you’re there by paying careful attention to everything that’s said and done.

Samir acts as a care partner to his brother, who was diagnosed with NSCLC in 2021. “Sometimes not being the patient allows the care partner to think out of the box and come up with options and recommendations,” Samir said.

Helen felt similarly. She noted that side effects can sometimes get in the way of understanding things. “Sometimes the caregiving requires details on all the potential treatments and the patient can’t process so much information,” Helen said.

The impact of side effects shouldn’t be underestimated. Min’s husband, for example, experienced many, including fatigue, diarrhea, digestive issues,

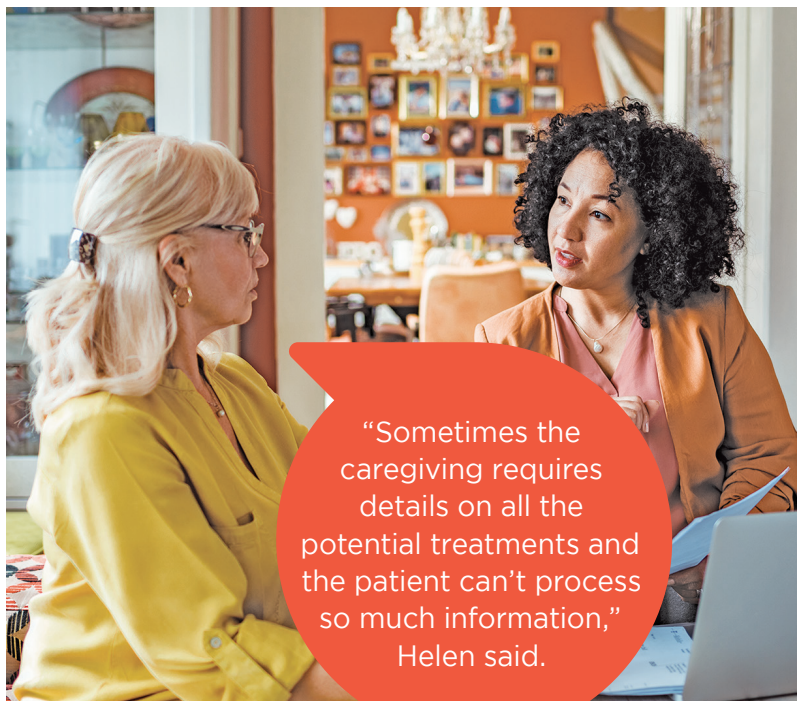


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“Sometimes the caregiving requires details on all the potential treatments and the patient can’t process so much information,” Helen said.

balance problems, brain fog, and paronychia—an inflammation of tissue near the nails that can be very painful.<sup>27</sup> This is all the more reason to write down what their healthcare team is saying. If it’s too hard to take notes and stay present during the appointment, consider recording the call. Min took notes and recorded appointments, too.

Ask your healthcare team if you can get a copy of all test results or take a picture of those documents with your phone during your appointment. Reviewing those files later could help you make some important decisions—with confidence! That might help you and the person you’re helping sleep better at night.

“Based on my experience, I firmly believe that the patient and support person need to take ownership of this diagnosis. They must be the managers of their cancer treatment, as much as possible,” said Clara, whose husband was diagnosed with NSCLC in 2019.

The rise of telemedicine and video conferencing might make it easier for you to attend medical appointments. Find out if you can call in to appointments that you can’t attend in person, perhaps by connecting via video conference to your loved one’s phone.

## Recognize your own emotional needs

According to the survey, 80% of care partners said they agreed or completely agreed with the statement that “the patient’s responsibility is to focus on getting better; my role is to take care of everything else.” While that’s very altruistic, that kind of sentiment can also leave the care partner overwhelmed and unsupported.

It’s important as a care partner to recognize how a lung cancer diagnosis impacts you personally. Carter says that when he first heard the diagnosis, he felt a mix of anger, disbelief, empathy and sadness. But he also felt a sense of mission. Understanding NSCLC can help you feel some amount of control over a new and scary situation.

What emotions did you feel when you were first made aware that the individual for whom you provide care and/or support was diagnosed with non-small cell lung cancer (NSCLC) with Exon 20 insertion mutation? (please check all appropriate)

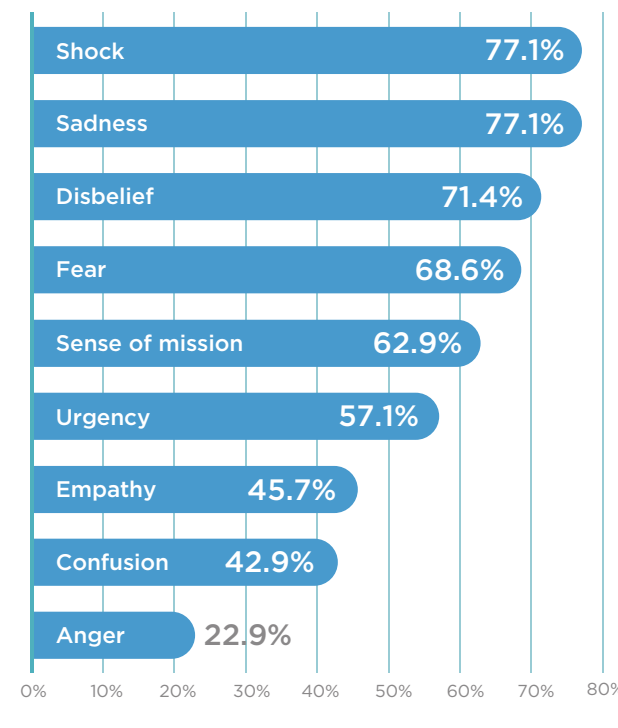


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Those feelings don’t just disappear a few weeks after diagnosis. Your own emotional needs—as well as those of the person you’re caring for—may grow. Jamar, whose wife was diagnosed with NSCLC in 2019, said family members, relatives, friends, and even doctors have provided him with emotional support.

Lucas’ wife was diagnosed with NSCLC in 2020. He appreciates that those closest to him expressed an interest but admits he doesn’t always feel comfortable divulging details. “Family and friends ask me how I am doing,” he said. “What else can you say but ‘good?’”

Min notes that care partners should not ignore their own needs for support and therapy. “I needed more support than he did. He still does not talk about it with a professional and I feel I am the recipient of all his fear, anger, and pain. This puts a huge strain on me as I try to deal with my own feelings which he cannot really process, so it’s a very lonely and stressful place to be.”

Who provides you with emotional support?



Image is not of actual patients.

## Participate in patient advocacy and social media groups for care partners

Min found support, in part, from her Imerman Angel Care Partner who had been through a similar situation. The Imerman Angels connect people dealing with cancer to cancer fighters, survivors, and care partners who provide insight and guidance as mentors.

Helen suggested joining a support group with other care partners. “It expands your knowledge quickly,” said Helen, who also attends a caregiver support group at a local cancer center. “I learned about treatments, life expectancy—lots of information about lung cancer—and eventually connected with other advocates for loved ones with the Exon 20 mutation.”

CancerCare.org offers counseling with social workers who specialize in cancer of all sorts. Additionally, the group hosts support groups online, over the phone, and in person at sites across America. (For a list of such groups, turn to the Helpful Resources and Support page.)

Many care partners surveyed found help in patient advocacy groups. Samir said social media groups—such as those on Facebook and Twitter—sponsored by patient advocacy organizations helped provide him with emotional guidance.

Patient advocacy groups are often organized around a specific disease or a subset of people with that disease. There are groups that are about all types of cancers, others specific to a certain organ or cell type, and still more tied to the biomarkers. They connect patients and care partners going through the same experiences, provide outreach, and publish materials in an effort to raise awareness and create a sense of community.

For example, those impacted by an Exon 20 insertion mutation can join the online community at Exon20group.org. Lucas says he feels lucky to have found the Exon 20 group, which “answered many questions and opened our eyes to her mutation.”

Achara felt similarly. “The best information I have received has been through my own efforts at finding support groups online,” Achara said. “The Exon 20 Group was our life saver as far as finding trials and treatments. I’ve met other patients through many sites to gain insight on side effects and managing side effects.”

The site SmartPatients.com offers discussion boards for a variety of types of lung cancer, including ROS1-positive and KRAS-positive patients. People with ALK-positive lung cancer, which involves the fusing together of two genes,<sup>28</sup> can find a community for their needs at AlkPositive.org. Search Twitter and Facebook for the name of your loved one’s mutations, too.

### What were the sources of information that you used to better understand non-small cell lung cancer (NSCLC) with EGFR insertion mutation and available treatments? (please check all appropriate answers)

Information that I found online by using Google and/or other search engines	80.0%
My doctor(s)	71.4%
Patient advocacy organizations/support groups that provide information/support specifically for non-small cell lung cancer (NSCLC)	71.4%
Online social media groups sponsored by patient advocacy organizations that provide information/support specifically for non-small cell lung cancer (NSCLC) with EGFR Exon 20 insertion mutation	60.0%
Other patients with non-small cell lung cancer (NSCLC) in online support groups or social media (such as Facebook)	45.7%
Patient advocacy organizations/support groups that provide information/support for multiple kinds of cancer	40.0%
Nurse practitioner, nurse, or other medical professional working with my doctor(s)	25.7%
Other	17.1%

A few of the care partners who got information via online advocacy and social media groups mentioned they learned a lot from others who were there about side effects. This is particularly important given that nearly 55% of care partners surveyed felt they did not receive adequate information, guidance, or training about managing side effects from anti-cancer medications. In fact, information often flowed in the opposite direction. More than 70% of care partners brought side effect treatment suggestions to the healthcare team for the person whom they supported.

What are the most serious side effects that the individual for whom you provide care and/or support experiences from their current treatment for NSCLC with the EGFR Exon 20 insertion mutation?

**RASH**  
**FATIGUE**  
**PARONYCHIA**  
**NAUSEA**  
**diarrhea**  
**PAIN**  
**LESIONS**  
**DEHYDRATION**  
**NONE**  
**Seizures**  
**Kidney failure**  
**Constipation**  
**Loss of appetite**  
**Scalp sores**  
**Weight loss**  
**Anxiety**  
**Balance**  
**Insomnia**  
**Fever**  
**Emotional distress**  
**Shortness of breath**  
**Coughing**  
**Pulmonary embolism**  
**Brain fog**  
**Intestinal issues**  
**Bowel issues**  
**Acid reflux**  
**Allergic reaction**  
**Loss of taste**

Image is not of actual patients.

Patient advocacy and social media groups can be eye opening. But consider what information you want to share with your loved one. Nearly 66% of survey respondents said they felt that care partners had different needs, in terms of information and support, than patients. A number of respondents said they had different needs specifically when it came to knowing about the course the disease will likely take.

Emilia helps care for her uncle who was diagnosed with NSCLC in 2018, along with his wife and daughter. “Sometimes when the prognosis is grim, the caregiver needs to hear the truth but the patient does not because he or she needs to keep hope alive,” she said.



Image is not of actual patients.

## Consider clinical trials as a potential treatment approach

While some of these treatment options have been approved by the US Food and Drug Administration (FDA) for patient use, others are being tested in clinical trials.<sup>20,21</sup> Clinical trials are research studies designed to see whether a particular treatment is safe and effective in people. A clinical trial might be part of your loved one's journey. A good place to start is with your healthcare team. They should know about trials in your area. Some care partners looked for clinical trials online.

"I did the bulk of the research to find options to help my parent make an informed decision," Talia said, in relation to clinical trials. Talia's mother was diagnosed with NSCLC in 2014.

Anya, who is also caring for her mother with NSCLC, said she emailed principal investigators and arranged for meetings to discuss her mother's participation in the trial. The principal investigator is the person in charge of the study and will know about factors that might rule someone out as a participant. The screening process for clinical trials typically took between one and four weeks. It is important to note, however, that clinical trials are not appropriate for everyone. A lot of factors can influence whether the patient can get into a clinical trial, including how much the disease has progressed and their past treatments. Geography can also play a role. Your loved one may need to travel to be part of a trial if one is not located near you.

Some of the care partners surveyed said they got information about clinical trials from their healthcare team, while others said they looked online. Some patient organizations and advocacy groups can also help in your hunt for clinical trials. Searching for online groups specific to your loved one's mutation could yield similar results.

## Moving forward with hope and empowerment

The hope, kindness, and care of friends or family can make a huge difference in the life of someone with cancer.

"Be patient, attentive, and positive as a direct support person to the patient," suggested Carter.

Your efforts, no matter how small, add up and make a difference.

"Sometimes, it's easy to get frustrated and lose patience as prolonged stress mounted," said Jamar. "Be strong, be positive. There is always help and hope."

"Be patient, attentive, and positive as a direct support person to the patient," suggested Carter.



Image is not of an actual patient.

### »» TAKE ACTION ««

- Think broadly about care and community
- Talk to your loved one about comprehensive biomarker testing
- Consider a lung cancer specialist as part of their medical team
- Explore financial assistance programs
- Keep a record of what happens at appointments
- Recognize your own emotional needs
- Participate in patient advocacy and social media groups for care partners
- Investigate potential clinical trials

## Helpful Resources and Support

### American Cancer Society

800-227-2345 helpline;  
<https://www.cancer.org/>;  
<https://www.facebook.com/AmericanCancerSociety/>;  
<https://twitter.com/americancancer>

This national organization is on a mission to free the world from cancer by funding and conducting research, sharing expert information, supporting patients, and spreading the word about prevention. It offers a wide variety of information and services to patients and their families.

### American Lung Association

1-800-LUNG-USA;  
<https://www.lung.org/>;  
<https://www.facebook.com/lungusa/>;  
<https://twitter.com/LungAssociation>

The American Lung Association's mission is to save lives by improving lung health and preventing lung disease. We do this through education, advocacy, and research.

### ALK Positive

<https://www.alkpositive.org/>;  
<https://www.facebook.com/alklungcancer/>;  
<https://twitter.com/ALKLungCancer>

A support community where ALK-positive lung cancer patients and caregivers could share their personal experience with this condition.

### American Society of Clinical Oncology (ASCO)

<https://www.cancer.net/>;  
<https://www.facebook.com/CancerDotNet/>;  
<https://twitter.com/cancerdotnet>

Trusted, compassionate information for people with cancer and their families and caregivers from the organization considered the voice of the world's cancer physicians and oncology professionals.

### CancerCare

800-813-4673;  
[info@cancer.org](mailto:info@cancer.org);  
<https://www.cancer.org/>;  
<https://www.facebook.com/cancercare/>;  
<https://twitter.com/cancercare>

A national organization that provides free, professional support services and information designed to help those with cancer manage its emotional, practical, and financial challenges.

### Cancer Support Community

<https://www.cancersupportcommunity.org/>;  
<https://www.facebook.com/CancerSupportCommunity/>;  
<https://twitter.com/CancerSupportHQ/>;  
<https://www.CancerSupportCommunity.org/non-small-cell-lung-cancer/>;  
<https://www.CancerSupportCommunity.org/Biomarker-Tool>

A global nonprofit network of 175 locations, delivering more than \$50 million in free support and navigation services to patients and families. In addition, the Cancer Support Community administers a toll-free helpline and produces award-winning educational and digital resources. The network also conducts cutting-edge research on the emotional, psychological, and financial journey of cancer patients and advocate at all levels of government for policies to help individuals whose lives have been disrupted by cancer.

### Caregiver Action Network (CAN)

<https://www.caregiveraction.org/>;  
<https://www.helpforcancercaregivers.org>

Caregiver Action Network (CAN) is the nation's leading family caregiver organization working to improve the quality of life for the more than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age.

CAN is a non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge.

### CaringBridge

<https://www.caringbridge.org/>

For nearly 25 years, CaringBridge has made it simple and safe to offer or ask for support. More than 300,000 people use the free, private, secure, and ad-free online platform every day to share health updates and rally family and friends around a loved one's health journey.

### EGFR Resisters

<https://egfrcancer.org/>;  
<https://www.facebook.com/groups/EGFRResisters/>;  
<https://twitter.com/EGFRResisters>

A grassroots, patient-driven community dedicated to changing EGFR-mutated lung cancer into a manageable chronic disease. Specifically, the group focuses on driving research aimed at finding treatments for patients with EGFR-mutated lung cancer that has become resistant to treatment.

Takeda Oncology is not affiliated with these organizations. By listing these resources, Takeda Oncology is not endorsing any particular service or group and we are not responsible for the services provided. They are provided here for informational purposes and are not meant to replace your healthcare provider's medical advice.

## Helpful Resources and Support (Continued)

### European Society for Medical Oncology (ESMO)

<https://www.esmo.org/>;  
<https://www.esmo.org/for-patients/patient-guides>;  
<https://www.facebook.com/esmo.org>;  
<https://twitter.com/myesmo>

Improving the quality of cancer care, from prevention and diagnosis to palliative care and patient follow-up, is the core mission of ESMO. The organization seeks to educate doctors, patients, and the public about best practices and the latest advances in oncology, as well as to promote equal access to optimal cancer care for all patients. Among the information this organization offers is a collection of patient guides that can be found online.

### Exon 20 Group

602-618-0183;  
[exon20@exon20group.org](mailto:exon20@exon20group.org);  
[Exon20group.org](http://Exon20group.org)

An international multi-stakeholder organization of patients, care partners, thoracic/medical oncologists, NGS labs, and pharmaceutical/biotech partners, co-founded with EGFR Exon 20 patient Kevin M. Hanlon and his brother Robert T. Hanlon, PhD, dedicated to turning EGFR Exon 20 insertions and HER2 Exon 20 insertions into chronic diseases through providing advocacy, funding research, and accelerating drug development through its Exon 20 International Research Consortium. Patients and their care partners can receive case navigation, second opinion referrals, oncology nursing services, assignment of an “Angel Buddy” mentor, strategies for managing side effects, clinical trials matching services, comprehensive biomarker testing matching services, and invitations to participate in conferences and online support groups, including Facebook (<https://www.facebook.com/groups/136311127056022/>) and Inspire (<https://www.inspire.com/groups/exon-20/>).

### Family Reach

<https://familyreach.org/ftp/>;  
<https://www.facebook.com/familyreach/>;  
<https://twitter.com/familyreach>;  
<https://www.instagram.com/familyreach>

Family Reach is a national nonprofit organization that helps families manage the many costs of cancer. Services include financial education, financial coaching, and resource navigation to patients and caregivers facing a cancer diagnosis.

### GO2 Foundation for Lung Cancer

800-298-2436 helpline;  
202-463-2080 general questions;  
[info@go2foundation.org](mailto:info@go2foundation.org);  
<https://www.facebook.com/GO2Foundation/>;  
<https://twitter.com/go2foundation>

Founded by patients and survivors, the aim of GO2 Foundation is to transform survivorship through work devoted to saving, extending, and improving the lives of people who are vulnerable to, at risk for, or diagnosed with lung cancer. The organization’s goals include ending stigma, increasing public and private funding for research, and ensuring access to care.

### Imerman Angels

<https://imermanangels.org/>;  
<https://twitter.com/imermanangels>;  
<https://www.facebook.com/ImermanAngels>

Imerman Angels partners anyone, any age, any gender, anywhere and any cancer type seeking support with someone just like them – a “Mentor Angel.” A Mentor Angel is a cancer survivor or caregiver who most importantly has faced the same type of cancer.

### Inheritance of Hope

<https://inheritanceofhope.org/>;  
<https://www.facebook.com/InheritanceOfHope>;  
[https://www.instagram.com/inheritance\\_of\\_hope/](https://www.instagram.com/inheritance_of_hope/)

Inheritance of Hope inspires hope in young families facing the loss of a parent. The 501(c)(3) charity offers on-site Legacy Retreats®, online Hope@Home™ weekends, and monthly groups for all ages – all with other families who “get it.”

### International Association for the Study of Lung Cancer (IASLC)

<https://www.iaslc.org/>;  
<https://www.facebook.com/IASLC>;  
<https://twitter.com/IASLC>

Incorporating the involvement of cancer specialists, patients, and caregivers, this organization is the only global network dedicated to the study and eradication of lung cancer and other thoracic malignancies. By hosting global conferences, funding science, and informing the healthcare and patient communities, it strives to improve care through research, clinical practice, care delivery, and advocacy. Its website offers a variety of informational resources, including current news in the lung cancer arena.

### Living With EGFR Exon 20 Insertion Takeda webpage

<https://www.livingwithexon20.com/>

This page offers information on, and tips for living with, the disease and lists resources for patient support.

### Lung Cancer Foundation of America

<https://lcfamerica.org/>;  
<https://facebook.com/lungcancerfoundation>;  
<https://twitter.com/LCFAmerica>

LCFA’s mission is the improvement in survivorship of lung cancer patients through the funding of transformative science. While raising funds to support lung cancer research, LCFA will raise the public’s awareness and serve as a resource for patients or anyone seeking answers, hope, and access to updated treatment information, scientific investigation, and clinical trials.

### Lung Cancer Research Foundation

Patient Support: (844) 835-4325;  
<https://www.lcrf.org/support>;  
<https://www.facebook.com/LungCancerResearchFoundation>;  
[https://twitter.com/lcrf\\_org](https://twitter.com/lcrf_org)

The mission of the Lung Cancer Research Foundation (LCRF) is to improve lung cancer outcomes by funding research for the prevention, diagnosis, treatment, and cure of lung cancer. LCRF offers free patient and caregiver educational materials as well as a toll-free lung cancer support line.

### LUNGevery

844-360-5864 HELPLine; 312-407-6100;  
<https://www.lungevity.org>;  
<https://www.facebook.com/lungevity/>;  
<https://twitter.com/LUNGevery>;  
<https://www.lungevity.org/noonemissed>

Provides support, community, and information to people affected by lung cancer. The organization also sponsors a Facebook group for people with NSCLC that has the EGFR Exon 20 insertion mutation, as well as an online support group for people with EGFR-mutated NSCLC. The No One Missed website (<https://www.lungevity.org/noonemissed>) highlights the importance of comprehensive biomarker testing in NSCLC.

### Patient Advocacy Foundation

<https://www.patientadvocate.org/>;  
<https://www.facebook.com/patientadvocatefoundation>

Patient Advocate Foundation (PAF) is a national 501 (c)(3) non-profit organization that provides case management services and support services to people living with cancer and other chronic, life-threatening and debilitating illnesses. These services include helping patients, families and caregivers navigate the healthcare system and identifying local, regional, and national resources to solve access and affordability issues.

### Smart Patients

<https://www.smartpatients.com>;  
<https://www.facebook.com/smartpatientscommunity/>;  
[https://twitter.com/smart\\_patients](https://twitter.com/smart_patients)

Smart Patients is an online community for patients and families affected by a variety of illnesses. Here, you can learn at your own level about scientific developments related to your condition, share your questions and concerns with other members, and use what you learn in the context of your own life.

### Triage Cancer

<https://tragecancer.org/>;  
<https://www.facebook.com/TriageCancer>;  
<https://twitter.com/TriageCancer>

Triage Cancer is a national, nonprofit organization that provides free education on the practical, insurance, employment, and financial issues that may impact individuals diagnosed with cancer and their caregivers, through events, materials, and resources.

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**the care card**

With comprehensive biomarker testing, your loved one will know all about their cancer. Make sure their healthcare team knows the details, too! Fill out your own Cancer Information Sheet and keep a copy in your wallet or purse so you'll have it with you for all of your appointments.

Fold here →

This care card is for \_\_\_\_\_

They have non-small cell lung cancer.

They were diagnosed in 

day	month	year
<input type="text"/>	<input type="text"/>	<input type="text"/>

#### Their Biomarkers:

Name of Mutation 1: \_\_\_\_\_

Location: \_\_\_\_\_

Name of Mutation 2: \_\_\_\_\_

Location: \_\_\_\_\_

#### Their Current Treatment Regimen:

\_\_\_\_\_

#### Their Past Treatments:

\_\_\_\_\_

\_\_\_\_\_

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## Survey Objectives

For nearly two and a half centuries, Takeda's mission has been to improve people's health, and we have built upon that heritage by developing and delivering life-changing treatments to patients—for example, those who have NSCLC with the rare *ALK* gene mutation. Today, our commitment to science, collaboration, and innovation fuels our continued dedication to creating care options for people affected by cancer, including those with NSCLC with the EGFR Exon 20 insertion mutation.

To more fully meet the needs of the patients and care partners we serve, we also consider it essential to provide meaningful quality of life support. As a patient committed to becoming your own best advocate or as someone who supports that journey, you may be seeking guidance about how to best conduct online fact-finding, get emotional support, and select and work with doctors who are experts in both lung cancer and the use of biomarker testing, which is important because it can help diagnose and track your disease and guide its care.

The bottom line is that you may appreciate information that can help empower you in that search. That's why we worked with the Exon 20 Group to conduct this survey and share its results.

Like Takeda, the Exon 20 Group is devoted to those affected by NSCLC with the EGFR Exon 20 insertion mutation. The Exon 20 Group has pledged to advance the discovery and approval of promising Exon 20-targeted drugs, help patients and their families thrive through treatment, and connect clinicians and other stakeholders with the community of people affected by NSCLC with the EGFR Exon 20 insertion mutation.

Through this partnership with the Exon 20 Group, we're excited to be able to extend a hand to you. We're also thrilled that the findings of this study will expand the wisdom and hope we helped develop within the lung cancer community over the past decade.

## Survey Methodology

The "Rare, But Not Alone" survey was designed by Takeda with the help of a roundtable of experts who collaborated to design a set of 86 questions that addressed the issues most relevant to those affected by NSCLC with the EGFR Exon 20 insertion mutation.

Administered online, the survey was conducted from June 30, 2021, to July 31, 2021, by leaders of the Exon 20 Group and the EGFR Resisters organization among their members, including some outside the United States. The survey was presented in English.

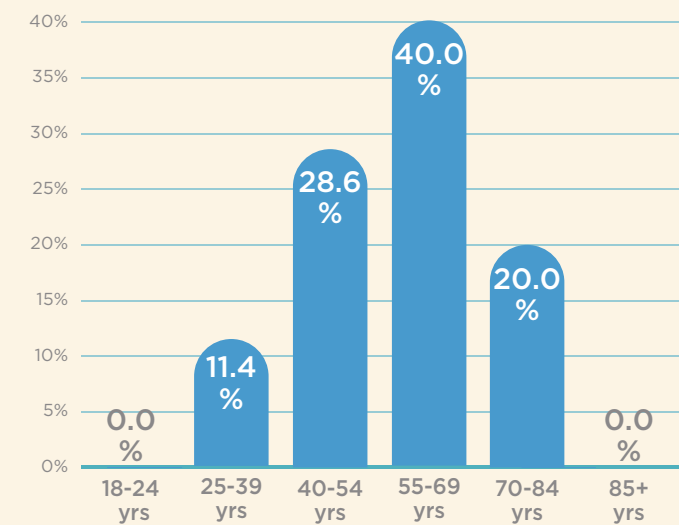
Within the population that initially agreed to take part in the survey, participants were self-selected. Some 54 people started the survey but 19 dropped out after the first question, regarding whether or not they cared or provided support for something you had NSCLC with the Exon 20 insertion mutation. Aside from the answer to that question, the results shown here represent the remaining 35 people. Some participants opted not to answer one or more questions.

Because most were connected with advocacy organizations before they took the survey, participants may have demonstrated a higher level of understanding about their disease, along with its diagnosis and treatments, compared with the overall population of those caring for people with NSCLC that have the EGFR Exon 20 insertion mutation. However, this may ultimately have been beneficial, as participants were able to share considerable expertise about the resources they found most helpful, as well as advice about how to connect with them.

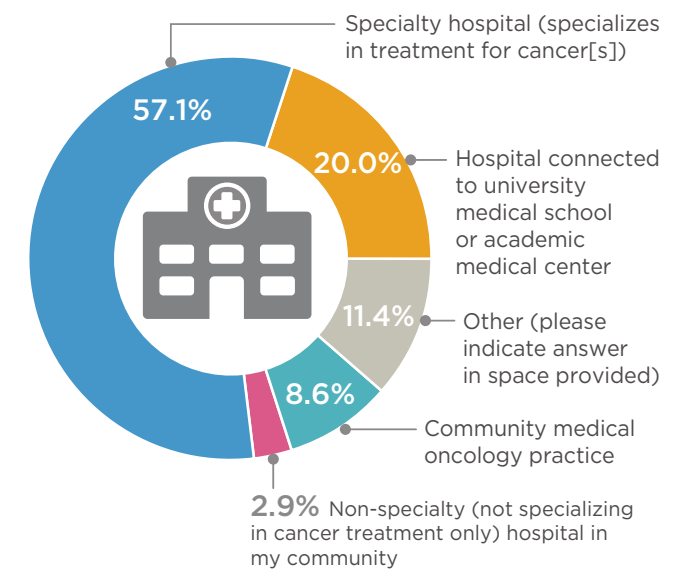
## Survey Details

Some tables do not total 100% due to rounding.

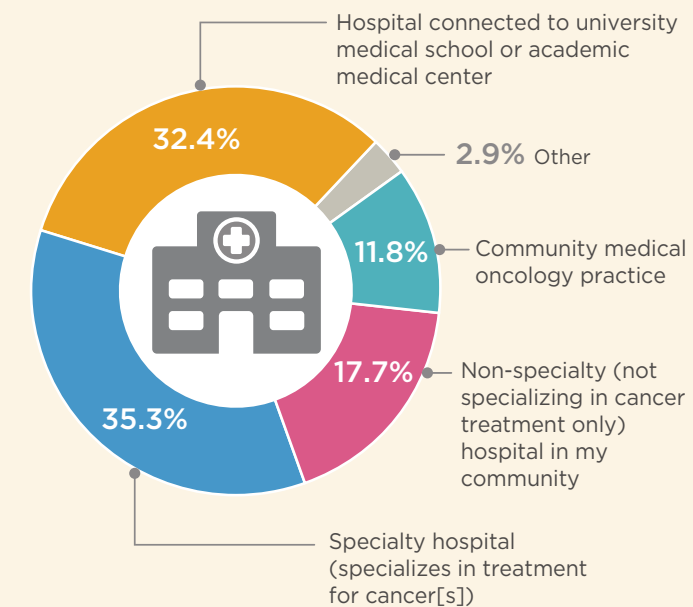
What is the age of the individual for whom you provide care and/or support?



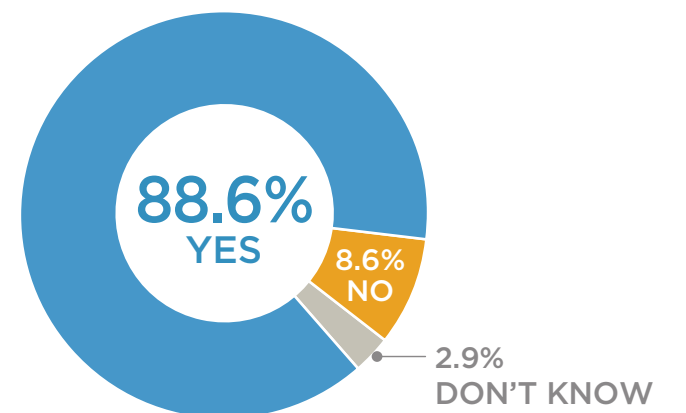
At what type of hospital, medical center, or medical practice is the individual for whom you provide care and/or support currently being treated?



Where (what type of hospital or medical practice) was the individual for whom you provide care and/or support first treated?



Does the current oncologist treating the individual for whom you provide care and/or support for non-small cell lung cancer (NSCLC) with the EGFR Exon 20 insertion mutation specialize in lung cancer?

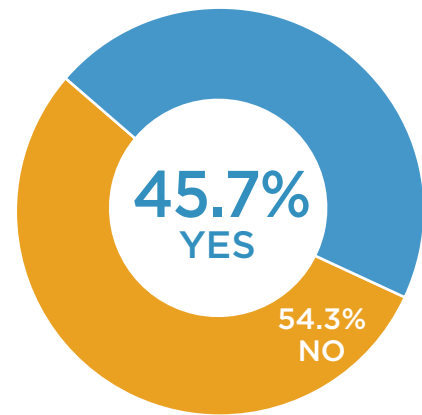


Name of Oncologist:

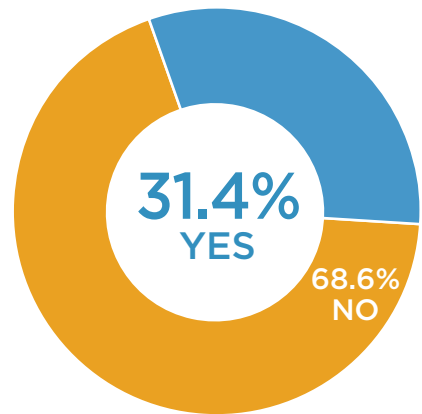
Notes:

## Survey Details (Continued)

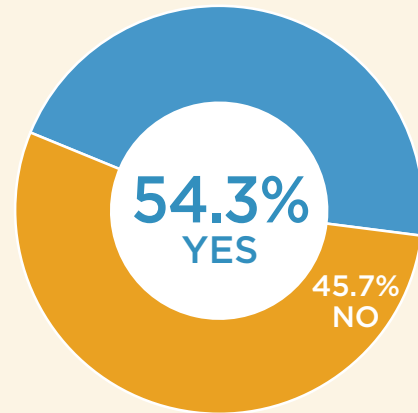
Does the individual for whom you provide care and/or support engage in sports and/or physical activity/exercise?



Are you the sole provider of care and support for the individual with non-small cell lung cancer (NSCLC) with the EGFR Exon 20 insertion mutation?



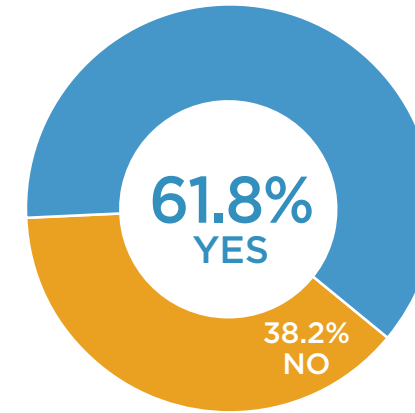
Has offering care and support to the individual with non-small cell lung cancer (NSCLC) with the EGFR Exon 20 insertion mutation impacted you financially?



If you answered Yes on the previous question, how has offering care and support to the individual with non-small cell lung cancer (NSCLC) with the EGFR Exon 20 insertion mutation impacted you financially? (please check all appropriate answers)

Limit or adjust my work schedule/responsibilities	45.5%
Cost of travel and accommodations when accessing care	42.4%
It has not impacted me financially	42.4%
Resulted in lost income	33.3%
Cost of medications	30.3%
Cost of treatment requirements such as laboratory services and scans other than direct cost of medications	21.2%
Child care	9.1%
Other	9.1%

Has living with non-small cell lung cancer (NSCLC) with the EGFR Exon 20 insertion mutation impacted the individual for whom you provide care and support financially?



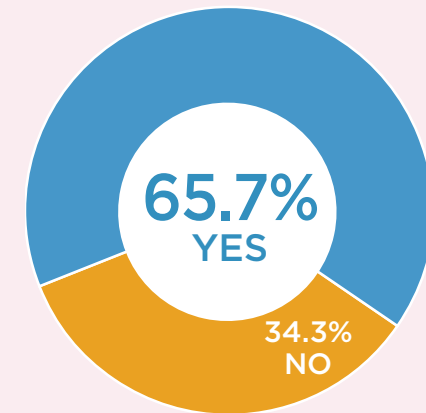
If you answered Yes on the previous question, how has living with non-small cell lung cancer (NSCLC) with the EGFR Exon 20 insertion mutation impacted the individual for whom you provide care and support financially? (please check all appropriate answers)

Cost of medications	51.6%
Cost of travel and accommodations when accessing care	48.4%
Limit or adjust their work schedule/responsibilities	45.2%
Resulted in lost income	45.2%
Cost of treatment requirements such as laboratory services and scans other than direct cost of medications	38.7%
It has not impacted them financially	25.8%
Other (please specify)	22.6%
Child care	12.9%

To what extent do you agree with this statement? "The patient's responsibility is to focus on getting better; my role is to take care of everything else."

Completely Agree	40.0%
Agree	40.0%
Neutral	11.4%
Disagree	8.6%
Completely Disagree	0.0%

Do you believe that the care partner has needs for information and/or support that are different than that needed by the patient?



At approximately what time after the individual for whom you provide care and/or support was diagnosed did you begin to do your own research on non-small cell lung cancer (NSCLC) with EGFR Exon 20 insertion mutation and available treatments?

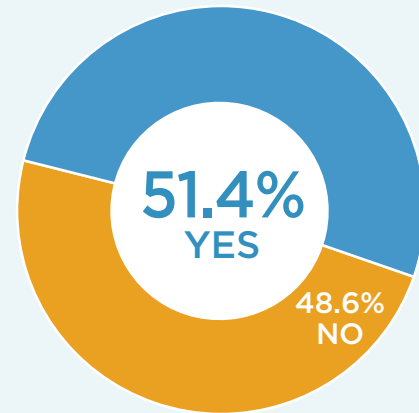
Directly after diagnosis (within 1 week)	91.4%
2-4 weeks after diagnosis	2.9%
1-3 months after diagnosis	2.9%
3-6 months after diagnosis	0.0%
6 months-1 year after diagnosis	0.0%
More than 1 year after diagnosis	2.9%
Other	0.0%

## Survey Details (Continued)

To what extent do you agree with this statement? “Most of the information and education that I receive(d) regarding non-small cell lung cancer (NSCLC) with EGFR Exon 20 insertion mutation came from my own research, not from the healthcare team.”

Completely Agree	28.6%
Agree	51.4%
Neutral	14.3%
Disagree	5.7%
Completely Disagree	0.0%

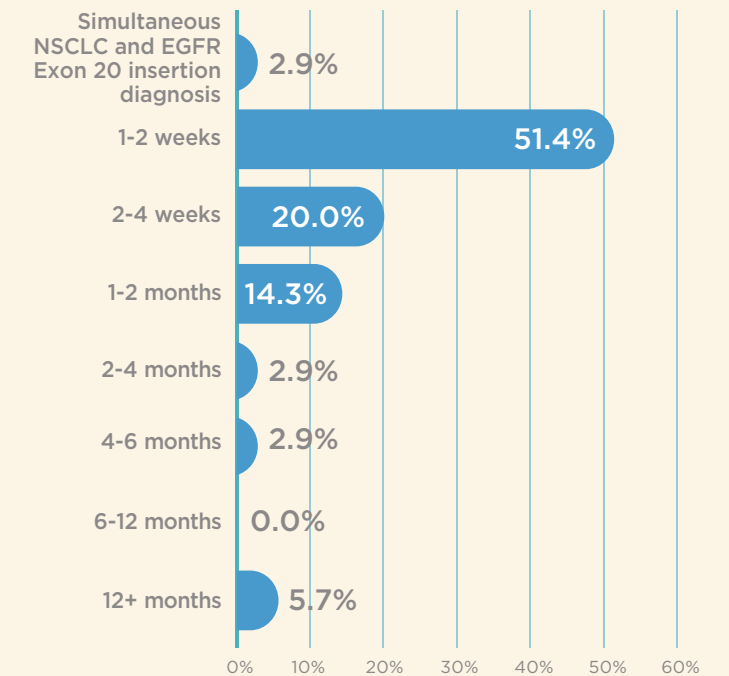
Do you believe that you and the individual for whom you provide support and/or care received enough information at the doctor visits after diagnosis of non-small cell lung cancer (NSCLC) with EGFR Exon 20 insertion mutation to make good decisions about what to do next?



After receiving all information available to you to support making a decision about the person whom you support’s treatment, what level of comfort did you feel to help with decision-making?

Very comfortable	20.0%
Somewhat comfortable	54.3%
Neither uncomfortable nor comfortable	14.3%
Somewhat uncomfortable	5.7%
Very uncomfortable	5.7%
Other (please specify)	0.0%

How much time passed from the time the individual for whom you provide care and/or support was first diagnosed with non-small cell lung cancer (NSCLC) and the time it was recommended that genetic mutation testing (changes in genes that may help identify the specific kind of NSCLC) should be performed? (please check one)



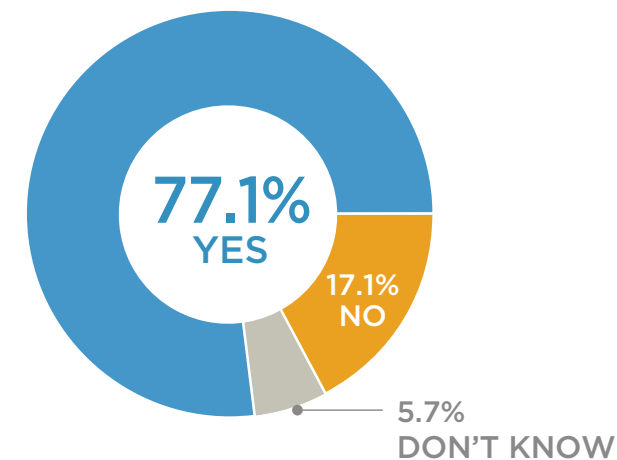
To what extent do you agree with this statement? “For me, the best source of information about non-small lung cancer (NSCLC) with EGFR Exon 20 insertion mutation and how to support the individual with this diagnosis are other caregivers.”

Completely Agree	3.0%
Agree	31.0%
Neutral	43.0%
Disagree	14.0%
Completely Disagree	9.0%

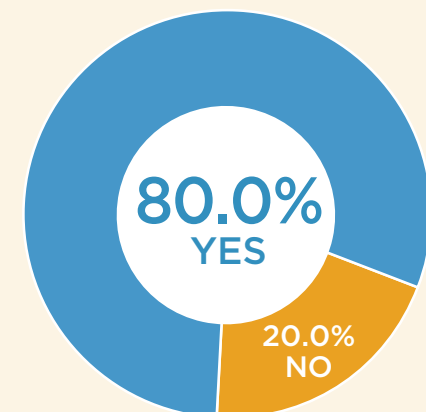
What role did you play in deciding on the best treatment for the individual with non-small cell lung cancer (NSCLC) for whom you provide care and/or support after their initial diagnosis? (please check all that apply)

The treatment decisions were made in partnership with the doctor and the individual for whom I provide care and/or support through shared decision-making	54.3%
The treatment decisions were made by the doctor with information provided by the individual for whom I provide care and support and me	22.9%
The treatment decisions were made completely by the doctor	17.1%
The treatment decisions were made by my doctor with assistance of the information we were provided by advocacy organizations	17.1%
I played a key role in deciding what the best treatment would be	17.1%
Other (please specify)	8.6%

Did the doctor provide you or the individual whom you provide care and/or support for with a printed copy of the final report from the genetic mutation testing?



Did your attitude/emotions change when the EGFR Exon 20 insertion mutation was first identified? (please check one)



## Survey Details (Continued)

What treatment options, if any, were presented to the person you provide care/support for, once the EGFR Exon 20 insertion mutation was identified?	
Since the individual for whom I provide care and/or support had not yet had any treatment, their oncologist recommended a first-line regimen of Alimta (pemetrexed) plus carboplatin	26.9%
Since the individual for whom I provide care and/or support had not yet had any treatment, their oncologist recommended a first-line regimen of chemotherapy	15.4%
Since the individual for whom I provide care and/or support had not yet had any treatment, their oncologist recommended a clinical trial	26.9%
Since the individual for whom I provide care and/or support had not yet had any treatment, their oncologist recommended an FDA-approved TKI for EGFR mutations (e.g. gefitinib, erlotinib, afatinib, dacomitinib, and osimertinib)	3.9%
After the oncologist discovered that the individual for whom I provide care and/or support had an EGFR Exon 20 insertion mutation, they took them off their current regimen and put them onto an FDA-approved TKI for EGFR mutations (e.g. gefitinib, erlotinib, afatinib, dacomitinib, and osimertinib).	0.0%
After the oncologist discovered that the individual for whom I provide care and/or support had an EGFR Exon 20 insertion mutation, s/he took them off the current regimen and helped enroll them into a clinical trial	7.7%
Yes, after my oncologist discovered that the individual for whom I provide care and/or support had an EGFR Exon 20 insertion mutation, s/he took them off the current regimen and put them on Rybrevant™ (amivantamab-vmjw)	0.0%
Not Applicable/No treatment options were presented	3.9%
Other (please specify)	15.4%

How difficult was it to access and qualify for clinical trials for non-small cell lung cancer (NSCLC) with the EGFR Exon 20 insertion mutation?	
Not difficult at all	26.9%
Slightly difficult	26.9%
Neither difficult or not difficult	11.5%
Very difficult	26.9%
Extremely difficult	0.0%

How long was the screening process for the clinical trial, including testing to qualify for the trial?	
Less than a week	7.7%
1-2 weeks	30.8%
2-4 weeks	34.6%
Longer than a month	3.9%
Not applicable	23.1%

Does the individual for whom you provide care and/or support engage in sports and/or physical activity/exercise?

WALKING  
Yard work  
Playing with grandkids  
Dog walking

hiking  
jogging  
jujitsu  
SWIMMING

YOGA  
floor exercises  
stationary bike  
TREADMILL  
BIKING  
weight lifting

## Acknowledgments

### “Rare, But Not Alone” Survey Participants

This publication would not have been possible without the contributions of the dozens of people who participated in the online survey. We thank you for your time, your insights, and your honesty.



**Takeda Pharmaceutical Company** sponsored this report. Conducted by Takeda in collaboration with the Exon 20 Group, it discusses the results of a global survey of those caring for patients with NSCLC that have the EGFR Exon 20 insertion mutation.

Takeda Pharmaceutical Company is a global biopharmaceutical company focused on research and development that, for two-and-a-half centuries, has been developing life-changing potential treatments for groups of people who face a high level of need. Through its commitment to science and innovation and its passion for improving lives, the company is dedicated to delivering new kinds of care to patients across the world, including those who have hard-to-treat cancers.

In addition to its deep in-house expertise, Takeda has established a network of partnerships with other organizations with a goal of unlocking the most promising science while providing meaningful quality of life support to the communities it serves.

Learn more about Takeda at [takeda.com](http://takeda.com).

This article is for informational purposes only and is not intended to provide medical advice. Marcia K. Horn, Dr. Andre Liem, and Kathleen Phan received compensation from Takeda for their participation in this publication.



**The Exon 20 Group**, a nonprofit organization founded in 2017, is dedicated to turning EGFR Exon 20 insertion-mutated NSCLC and similar conditions into diseases that can be medically managed long-term by funding research and providing emotional and informational support. This international organization includes key stakeholders from more than 50 countries: patients and their care partners, oncologists who specialize in these cancers, oncology nurses, laboratory researchers, health regulatory experts, and pharmaceutical companies.

While drawing clinicians into the effort to speed up the discovery and quick approval of promising treatments, the Exon 20 Group is committed to helping patients and their loved ones thrive through the journey with NSCLC that has the EGFR Exon 20 insertion mutation. Through this group, patients and their care partners can receive case navigation, referrals for second opinions, assignment of an “Angel Buddy” mentor, strategies for managing side effects, help finding appropriate clinical trials, and invitations to participate in conferences and online support groups.

The Exon 20 Group makes a simple but powerful pledge to each of its members: “We will never give up on you, and we will never leave you stranded.”

Learn more about this support organization at [exon20group.org](http://exon20group.org).

**The Patient Survey Roundtable** included 3 experts who helped shape the questions asked of participants. Using their experience across a variety of rare lung cancers, the roundtable members were asked to ensure that the survey addressed the issues that matter to caregivers of those facing NSCLC with the EGFR Exon 20 insertion mutation.



**Marcia K. Horn, JD**, of Phoenix, Arizona, has been president and CEO of the International Cancer Advocacy Network (ICAN) since 1997 and executive director of the Exon 20 Group since 2017.

Named a top-rated health nonprofit by GreatNonprofits.org, ICAN has navigated complex cases of stage IV cancer for more than 15,000 patients, families, and caregivers worldwide, with a goal of increasing survival while providing the highest possible quality of life. Within ICAN, the Exon 20 Group is a working group and international coalition dedicated to increasing treatment options for patients who have either of 2 unusual genetic mutations that contribute to cancer's growth, including the EGFR Exon 20 insertion mutation.

Ms. Horn's additional involvement across the cancer community includes membership in the SWOG Cancer Research Network's Early Therapeutics and Rare Cancers Committee, an advocacy role for the Stand Up 2 Cancer Lung Cancer Interception Dream Team, and service as a research advocate for the National Cancer Institute's Lung Specialized Program of Research at the University of Texas Southwestern and as an ambassador to the Patient-Centered Outcomes Research Institute. In her home state, she spearheaded a lobbying effort that resulted in the Arizona legislature providing \$10 million to fund the Arizona Anticancer Drug Discovery and Development Act of 1998.



**Andre Kiem D. Liem, MD**, is a medical oncologist and hematologist with City of Hope Comprehensive Cancer Center in Long Beach Elm, Long Beach Worsham, and Torrance. Dr. Liem also works as an assistant Clinical Professor in the Department of Medical Oncology & Therapeutics Research at City of Hope. He had been affiliated with Pacific Shores Medical Group in Long Beach, California, since 1999. There, he was director of the clinical research program, serving as an investigator in numerous clinical trials, including those testing anticancer treatments designed for patients with NSCLC driven by the EGFR Exon 20 insertion mutation.



**Kathleen Phan** is a project manager for the clinical trials office at City of Hope Comprehensive Cancer Center in Long Beach, California. She is skilled in all aspects of clinical trial coordination across studies in various medical areas, including oncology, hematology, and urology. Phan has worked with City of Hope, formerly, Pacific Shores Medical Group, since 2017, first as a patient coordinator, then as a clinical research coordinator, and now as a senior clinical research coordinator. In that role, she serves as lead clinical research coordinator and a sub-investigator on phase I to IV clinical trials at 7 clinic sites that provide 14 medical experts to participate as investigators. The trials she has supported include several with recently published results that tested anticancer treatments designed for patients with NSCLC driven by the EGFR Exon 20 insertion mutation.



We offer special thanks to the **EGFR Resisters** for also fielding this survey among its members. EGFR Resisters is an organization for people living with lung cancer that is sparked by an EGFR gene mutation and has become resistant to targeted treatment—drugs designed specially to fight a specific type of cancer. The group's aim is to drive important research questions and fund new science and clinical trials.

**Adenocarcinoma:**

The most common type of tumor cell involved with lung cancer cases in the US, typically found in the lining of the organ.<sup>4</sup>

**ALK gene:**

The anaplastic lymphoma kinase gene, which contributes to cell growth and division. Mutations to the *ALK* gene can contribute to the development of cancer.<sup>30</sup>

**Biomarker testing:**

Tissue or fluid testing for mutations that were not inherited. The results of these tests can help identify the best type of treatment for your cancer.<sup>11</sup>

**Chronic disease:**

A disease that continues for at least 1 year and requires ongoing medical attention, limits daily activities, or both.<sup>31</sup>

**Clinical trial:**

A research study that includes human patients who receive medical treatment with the goal of determining the health outcomes of the therapy.<sup>32</sup>

**DNA:**

Deoxyribonucleic acid is a chemical sequence found in cells that acts as instructions information for building and maintaining an organism.<sup>33</sup>

**Driver mutation:**

A mistake in a gene that contributes to the development of cancer.<sup>34</sup>

**EGFR Exon 20 insertion mutation:**

The addition of extra genetic information in the Exon 20 section of the EGFR gene.<sup>15</sup>

**EGFR gene:**

The epidermal growth factor receptor gene, which contributes to the process of cell growth and survival.<sup>15</sup>

**FDA:**

The Food and Drug Administration is a US agency that regulates clinical trials.<sup>35</sup>

**Genes:**

Inherited chemical sequences in the body, known as DNA, that determine a person's physical characteristics.<sup>36</sup>

**Lung cancer:**

A disease that starts in the lungs, cells then grow out of control.<sup>37</sup>

**Mutation:**

A change in DNA. It can result from copying mistakes that happen when cells divide, exposure to some chemicals, types of radiation, and viruses. Some mutations are inherited.<sup>38</sup>

**Next-Generation Sequencing (NGS):**

A process for testing DNA samples for mutations. This method has more discovery power than another commonly used method: polymerase chain reaction (PCR).<sup>23</sup>

**NSCLC or non-small cell lung cancer:**

The most common type of lung cancer.<sup>3</sup>

**Oncologist:**

A doctor who specializes in treating cancer.<sup>39</sup>

**Patient advocacy group:**

An organization, often nonprofit, that works to inform, support, and advocate on behalf of patients.<sup>40</sup>

**Polymerase Chain Reaction (PCR):**

A process for testing DNA samples for mutations. This kind of test is also more widely available than next-generation sequencing (NGS).<sup>22</sup>

**Prognosis:**

The course a particular disease is likely to take.<sup>41</sup>

**Side effect:**

An unintended and typically unwanted health effect that arises from treatment with a drug.<sup>42</sup>

**Support group:**

A group of people who provide emotional and informational support to help each other through a challenging shared experience, sometimes led by a professional facilitator.<sup>43</sup>

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