

Ask the Right Question About Lung Cancer

Report - action plan
to transform the
Lung Cancer landscape
in Greece



#therightquestion





About FairLife Lung Cancer Care

FairLife - Lung Cancer Care is the only non-profit organization, exclusively dedicated to lung cancer in Greece. FairLife L.C.C.'s mission is to holistically support people impacted by lung cancer, aiming to improve their quality of life throughout their journey from diagnosis to treatment.

FairLife L.C.C. works:

- to raise public awareness about prevention and early diagnosis, so as to reduce mortality rates
- for the right to be informed about lung cancer
- to promote equal access to diagnostic methods, clinical trials and innovative treatments
- to indicate the need for psychological support for patients, their families and caregivers
- to eliminate lung cancer stigma related to smoking

FairLife L.C.C launches the awareness campaign “**Ask the right question**” about lung cancer, so as to highlight an important social issue - the stigma of lung cancer patients, related to the habit of smoking. The campaign was first launched in Canada and Australia, and is now being run in Europe, in Greece, FairLife L.C.C.

The campaign is under the auspice of:

Association of European Journalists, Global Lung Cancer Coalition (GLCC), Lung Cancer Europe (LuCE), Hellenic Society of Medical Oncology (HeSMO), Hellenic Association of Lung Cancer (HeALC), Hellenic Thoracic Society (HTS), Hellenic Society of Thoracic and Cardiovascular Surgeons (HCTSS), Hellenic Society of Radiation Oncology (HESRO), Hellenic Radiological Society, Hellenic Nurses Association, Hellenic Society of Thoracic and Cardiovascular Surgeons (HCTSS), Hellenic Psychological Society, Greek Patient Association, Hellenic Cancer Federation (ELLOK).

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Foreword

The present report addresses the socio-economic and mental health issues of Greeks impacted by lung cancer and aims to find solutions to the above related challenges.

This report may facilitate policy makers to form a framework which will promote effective and early diagnosis and treatment as well as provide a strong foundation for education, awareness and support, in order to reduce the stigma associated with the disease.

In this context, we will to begin to ask the right questions about lung cancer.

This report was conducted by the Laboratory of Health Economics and Management, University of Pireaus.



Executive Summary

Lung cancer is the second most prevalent form of cancer worldwide, with 2.21 million new cases in 2020, and at the same time the most fatal (1.8 million deaths in 2020).¹

According to the latest World Health Organization data available, lung cancer is the third leading cause of mortality in Greece, and first among all forms of cancer, accounting for 8,960 new cases (incidence) per year in Greece (13.9% of total new cancer cases) and 7,662 deaths.^{2,3}

This report - *action plan to transform the Lung Cancer landscape in Greece* has two objective aims. First, we work to improve education and awareness about lung cancer to ensure that patients have access to prompt and accurate diagnosis and appropriate treatments. Second, we work to advocate for the Greek health care system to integrate lung cancer prevention and treatment.

This report identifies challenges as follows:

- Access to prevention and early diagnosis
- Access to innovative treatments
- Stigma
- The need for psychosocial support



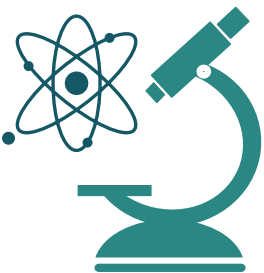
Prevention and early diagnosis

Lung cancer is an "invisible cancer"; therefore a very insidious disease. Today, only 16% of patients are diagnosed with localized lung cancer - when the disease is still in early stage. This is a significant challenge in that most patients show symptoms only, when lung cancer has already given metastases and become incurable. Early detection of lung cancer improves survival rates and allows for better treatment options. In addition to delayed diagnosis, poor information has been found to prevent communities from accessing lung cancer screening programs. In addition, the stigma surrounding lung cancer is an additional barrier to participation in screening programs.⁴

Based on the findings and analysis of data from a study conducted for the first time in Greece by the Health Policy Institute, under the scientific supervision of Professor of Health Policy, Dean of the Faculty of Social and Political Sciences, University of Peloponnese, Mr. Kyriakos Souliotis and Public Health Expert Dr. Evi Hatziandreou, it was documented that the implementation of lung cancer screening with low-dose CT scanning clearly benefits the health system and our society, as it has the potential to lead to earlier diagnosis, earlier treatment with better chances of cure and gain in human life. Based on a predictive, stochastic model, screening would lead to a significant reduction in deaths from lung cancer by 24.61% and a reduction in years of life lost by 30.9% in Greece.

Specifically, the model predicts 339 fewer deaths due to lung cancer and 944 fewer years of life lost per 100,000 within five years. The above figures are in line with similar studies in other countries. To this end, early and efficient access to screening, referral to multidisciplinary teams and personalized healthcare are required.⁵

The above actions are the best clinical practice and therefore have the potential to improve treatment outcomes.



Access to innovative treatments

Lung cancer progresses aggressively and patients' health can deteriorate fast. The importance of prompt diagnosis and treatment is crucial. While scientific advances and innovation in treatments are rapid, many patients still have to wait a long time to access the medication they need.

The first step in providing patients with appropriate targeted treatment is molecular testing (biomarker testing). This is done in a laboratory setting, where tissue from the patient's tumor is examined for actionable genetic alterations or in the expression of proteins with therapeutic relevance.

Currently, approximately 50% of lung cancer patients will present with a mutation for which an effective targeted therapy is available. This means that all patients potentially eligible for targeted therapy should have their tumor tested using laboratory methods, such as next generation sequencing (NGS), which can identify the most common as well as the rarest mutations.

This leads to longer survival and improved quality of life for lung cancer patients. Innovation in lung cancer transforms the treatment landscape and opens up new perspectives, offering significant hope to patients who until recently had limited therapeutic options. Yet, there is limited public awareness and lung cancer remains a low priority in Greek society. This results in limited resources and funding for research, compared to other forms of cancer.³

Patients' access to new treatments is also compounded by social and economic inequality as well as the rigid legal framework that hinders the process. Access to personalized treatment for lung cancer can be impeded, for example, by the lack of limited scope of biomarker testing.

Gaps in information about treatment options or the importance of early diagnosis, - particularly prevalent among people from socio-economically underprivileged groups - can create additional barriers to adequate diagnosis and care. A tailored approach should be adopted to reduce inequalities in access and clinical outcomes.



Stigma

Lung cancer can be linked to many factors. Smoking, environmental pollution, exposure to toxic agents and a positive family history are only some of the causes for development of the disease. While the majority of lung cancer cases are linked to smoking, other risk factors that can provoke lung cancer are often overlooked. This affects people with lung cancer whether they have a history of smoking or not.⁶ It is important, therefore, to realize that the stigma around smoking can act as a barrier to seeking appropriate care for lung cancer.

The stigma around lung cancer is based on the perception that lung cancer is necessarily the sole responsibility of patients, because of their smoking habit. People living with lung cancer can experience stigma by their environment, at work, by health care professionals and even by family and friends. This acts as an extra burden and builds up negative associations, as people do not feel worthy of care and compassion. People living with lung cancer report feeling shame and experiencing prejudice, whether they smoke, have smoked in the past, or never have smoked in their lives. At the same time, stigma also puts extra strain on the family and caregivers of lung cancer patients and adds to their emotional distress. Awareness campaigns and anti-smoking education are important to address lung cancer stigma and improve empathy towards people diagnosed with lung cancer.³

In fact, if you have lungs, you can get lung cancer.



The need for psychosocial support

People living with lung cancer experience frequent and profoundly negative emotions, including fear, anxiety, anger, distress, isolation and depression. Until recently, the medical community has focused primarily on lung cancer patients' survival, placing little emphasis on their psychological support.

Meanwhile, the need for a holistic approach towards people impacted by lung cancer is broadly recognized worldwide as a prerequisite to improve the mental health of patients, of caregivers and families, given the prevalence of the disease and the toll it takes on individuals, their families and their communities.

A Greek study shows negative correlation between family support and anxiety and a positive one between anxiety and pain.⁷ Access to information about the disease and psychosocial support is highly important. Support through participation in tailored programs gradually helps patients to manage anxiety and depression and improve the quality of life for lung cancer patients and their caregivers.

Positive psychology and mental wellbeing are now recognized as key levers for addressing lung cancer challenge and improving patient outcomes.

Overview

There are two types of lung cancer:

- **Small cell lung cancer (SCLC)**, which develops rapidly and often spreads to other parts of the body. This type of cancer is associated with smoking and is rarely detected in non-smokers.
- **Non-small cell lung cancer (NSCLC)** , which is the most common type of lung cancer (80-85% of cases) and develops more gradually. The main histological subtypes are: adenocarcinoma, squamous cell carcinoma and large cell carcinoma.

Cancer staging describes the spread of lung cancer, i.e. whether it is localized within the lung or has spread to the regional lymph nodes or other organs. Lungs are large organs, therefore symptoms appear only late during the tumor development.

Even if symptoms appear - including coughing and fatigue - they are often attributed to other benign conditions. This is why early lung cancer is difficult to detect.

Lung cancer in Greece



Greece ranks second in Europe, behind Serbia, in terms of lung cancer new cases and third, behind Hungary and Serbia, in terms of fatalities.⁸

- 76% of new cases are reported among men and 24% among women.
- The age-adjusted lung cancer mortality rate is 81.1 for men and 17.5 for women per 100,000 people, ranking Greece 12th in the world.³
- The five-year prevalence of the disease in Greece is estimated at 10,449 or 100.25 per 100.000.¹
- Lung cancer patients have a low 5-year life expectancy (about 20%), compared to the other most common cancers (breast, colorectal and prostate).

Although smoking in Greece has been decreasing over the last two decades, 1 in 4 adults smoked on a daily basis in 2019, which is among the highest rates across the European Union. Moreover, the decade-long period of fiscal austerity has had a significant impact on the social determinants of health in Greece, particularly among the most deprived population groups. The above situation has undermined efforts to minimize the incidence of preventable risk factors through the adoption of healthier lifestyles and has restricted public cancer prevention programs.

Lung Cancer Stigma

When someone is diagnosed with lung cancer, they are quickly confronted with the question "Did you smoke?".

Friends, relatives, healthcare professionals and more pose the question, as if to decide whether the person facing a life-threatening diagnosis "deserved it." In fact, the answer is very often used as a standard of how much care and support is provided.

The question "Did you smoke?" is rooted in a long-standing stigma based on the myth that lung cancer is solely a smokers' disease. It is not. If you have lungs, you can get lung cancer.

While it is accurate that smoking, especially cigarettes smoking, is the leading cause of lung cancer, this is just one part of the picture; smoking accounts for about 22% of all cancer deaths and 85% of lung cancer cases.

About 10-25% of lung cancer cases worldwide occur in people who have never been smokers or who have smoked less than 100 cigarettes altogether in their lifetime. Causes can vary from genetic mutations to air pollution, exposure to multiple cancer agents, lung diseases, etc. Scientific research has revealed the complexity of the disease as well as the association with various pathological and anatomic aspects.⁹

Nevertheless, people with lung cancer face blame and shame - whether they smoked or not. But even if they did smoke, it doesn't matter. Whatever a person's risk factors prior to their diagnosis, they deserve care and support afterwards.

"Did you smoke?" is the wrong question. The answer doesn't matter. It prolongs an unfair stigma that persists, in part, because smoking is seen as a bad habit rather than the serious addiction it actually is.

The sooner we end stigma, the earlier lung cancer patients will get the full support and help they need to face this enormous challenge.

Negative Effects of Lung Cancer Stigma

The myth that lung cancer is a disease of smokers can have fatal consequences.

Non-smokers may ignore the symptoms, falsely believing it would not be lung cancer, since they never smoked. Healthcare professionals may also dismiss lung cancer as the possible cause-origin of symptoms. As a result, valuable treatment time may be lost due to late diagnosis and more people may die from the disease.

On the other hand, many current or ex-smokers avoid going to the doctor to check their symptoms for fear of being criticized. As symptoms get worse, cancer can spread and the outcome turns out to be more adverse than it would have been if they had their symptoms checked, as soon as they suspected something was wrong.

The blame and stigmatization which follow lung cancer patients adds an emotional burden to an already distressing situation. Many experience guilt and shame - whether they smoked or not.

Lung cancer stigma also leads to hiding the diagnosis. Even within families, people are reluctant to talk about a loved one's lung cancer. Fear of judgment deprives patients, caregivers and their families of support, when they most need it.

We need to move the conversation about lung cancer from one of blame and shame to one that offers care and support. Thus, we can save lives.

The Role of Education in Addressing Lung Cancer Stigma

Public education is key to eliminating the unfair barrier and burden that stigma creates for people impacted by lung cancer.

Campaigns which have proven effective in changing perceptions need to be widespread and ongoing. Public funding is vital to support these efforts, as well as to educate the public about risk factors and symptoms.

Education for health care providers is also necessary. It should address the unconscious bias associated with lung cancer and how this bias affects healthcare. Primary care physicians may not always be aware of the possibility of earlier lung cancer diagnosis. So, further training is required to identify signs of the disease, particularly in high-risk groups, in order to avoid diagnostic delays.³ Healthcare providers should also be educated on how to support patients facing stigma as well as their families.

To further support healthcare providers' education, medical companies and professional bodies should systematically monitor attitudes and perceptions about lung cancer and lung cancer treatments. The presence of qualified mental health professionals is essential to address the burden of disease and lung cancer related stigma.

Training is also needed to improve treatment interventions in smoking cessation clinics, with a focus on treating smoking as an addiction rather than a behavioral choice.

On a personal level, we need to stop asking the wrong question - Did you smoke? - and start asking the right questions, so as to find effective ways to support people with lung cancer and ensure they receive the care and compassion they need and deserve.

Real Stories of Patients and Caregivers Who Felt the Lung Cancer Stigma

**We should all
have empathy**
for people fighting against
a serious disease.

It's a sign of civilization.

Milka's story



Milka has been diagnosed with lung cancer in 2021 and talks about the courage she found to move on, despite family issues and uncertainty about the future. She has felt the stigma associated with smoking and hopes for more empathy towards people impacted by lung cancer.

"Truth is I was overwhelmed at that time, because of family issues. I felt my body and soul exhausted and distressed.

A CT scan and a PET/CT scan confirmed the diagnosis. Despite her fear and distress, she knew she had to fight. She knew she had to be strong.

"I'm sure everyone has hidden powers they do not even realize. When all seems hopeless, we can be heroes. This is how I survive. This is how I move on."

Milka completed her treatments, chemotherapy, radiation and immunotherapy, always according to the doctors' instructions. She is now trying to recover and is slowly regaining her peace and balance. She attends counseling sessions and realizes she is not alone in her fight against lung cancer. She shares her pain and experience around lung cancer with other members of the group and together they discover how much they have in common.

"You have people around you who understand you, professional psychologists who can empathize with you and help you take the next steps."

She has been more of a passive smoker for many years than an active one. Through her adventure with lung cancer, she felt the stigma of the disease related to smoking.

"The question "Did you smoke?" was the first question I faced when people learned about my disease.

But in my counseling group, there are patients who have never smoked.

People need to be informed that anyone with lungs can get lung cancer.

We need to become more educated, more aware and more empathetic towards people who are fighting against a serious disease.

It is a sign of civilization."

“ People
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“ We need to become more educated, more aware and more empathetic towards people who are fighting against a serious disease.
It is a sign of civilization.”

Lung Cancer is a Marathon.

We skip Stigma.

We run to stay Healthy.



Christos' story

Christos is a lung cancer patient and he speaks about the importance of physical exercise to prevent and manage disease. He does not allow stigma affect him. Instead, he focuses on willpower and positive psychology.

Christos is 66 years old. About a year and a half ago, he has been diagnosed with lung cancer. He is currently in stage IV, with liver metastases and 10 small brain nodules. He receives targeted treatment, having tested positive for a specific biomarker, through molecular testing, which is the essential to face his own individual cancer.

"How could I face such a challenge? What should I tell my family? And myself?

I decided to stand up and fight. I have always been an athlete. Lung cancer didn't stop me. I saw the illness as a challenge, an opportunity to get stronger. I exercise every day, watch my diet and try to stay optimistic. Lung cancer is a marathon, not a race. "

Not all days are the same in this marathon, but Christos runs to stay healthy and to be around his family as much as possible.

Christos' daughter, Vassia, is worried about her father: "My dad is very important to me, I don't want to lose him. I'm scared, but I know he's a fighter and he's going to be OK."

"Physical exercise helps the immune system and generally works as prevention for any disease. Certainly, in the lung cancer journey there are quite a few obstacles, such as the smoking stigma.

Fear and negative emotions, often associated with the smoking habit, weigh us down emotionally. Mental health is so important for everyone impacted by lung cancer. We owe it to ourselves to get the psychological support we need to stand up to the disease."

Christos believes in information and a radical shift of mindset. Lung cancer is not a disease we should feel guilty about.

"I skip the stigma. I recommend exercise, contact with nature, positive psychology. I stand on those things that will help me live, move forward in my healing and never backward!"

“ My dad is very important to me, I don't want to lose him. I'm scared, but I know he's a fighter and he's going to be OK. ”

“ I skip the stigma. I recommend exercise, contact with nature, positive psychology. I stand on those things that will help me live, move forward in my healing and never backward! ”

Let's focus
on research
and innovation.

Not Stigma.

Polly's story



Polly has been diagnosed with stage IV lung cancer, adenocarcinoma, and shares with us her hope for the future. She tells us about the importance of molecular testing which changed her own treatment path. Polly urges us to leave the stigma behind and stresses the importance of a personalized approach through biomarker testing.

Polly's cancer journey starts many years ago in 2008 - it was breast cancer - which was successfully treated at the time. After surgery and therapy, she moved on to recovery. After many years, in April 2020, she has been diagnosed with stage IV lung cancer. Polly is not a smoker.

"The doctor initially didn't give me much hope. But I moved forward with the HOPE I had in me."

Following her doctor's recommendation to proceed with biomarker testing, Polly tested positive for a specific targeted mutation. This immediately paved the way for personalized treatment and better prospects for managing the disease. She wants to stress the importance of molecular testing after the initial diagnosis as soon as possible, so that patients can promptly receive the best possible treatment for the disease.

"Biomarkers help doctors determine the best treatment for each patient. Unfortunately, in Greece, not all biomarkers are yet reimbursed, and this aggravates health inequalities, as it may exclude patients from reaching cure with the right medication. These inequalities should be targeted by the state and focus should be placed on information, support and equal access for patients to molecular testing and new, innovative treatments."

Polly also talks about the necessity of having psychosocial support programs for patients, caregivers and family members, in order to face every day lung cancer challenges.

"There are more than a few challenges. Uncertainty about the future, stigma around smoking-related disease, physical and psychological stress. When you hear people's stories and listen to their experiences, you receive guidance to move forward."

Polly loves life. She wants to live. She sees holistic support as essential for those impacted by the disease, especially those who have been recently diagnosed. We can then heal emotionally and take the time to make the right decisions about life.

"Cancer to me is about being persistent and doing constant and thorough testing. It is also about educating society, being aware and using the energy and voice to advocate for anyone and everyone with lung cancer. Always on the side of science. But away from stigma!"

“ Unfortunately, in Greece, not all biomarkers are yet reimbursed, and this aggravates health inequalities, as it may exclude patients from reaching cure with the right medication.”

“ Cancer to me is about being persistent and doing constant and thorough testing. It is also about educating society, being aware and using the energy and voice to advocate for anyone and everyone with lung cancer.”

We see
the person
beyond the disease.

Maria's story



Maria is 49 years old and takes care of her mother who has advanced non-small cell lung cancer. Recently, her very best friend has been diagnosed with small cell lung cancer. Maria experienced lung cancer stigma from her first contact with health professionals. She stands up to any lack of empathy and respect toward patients and their loved ones. She encourages actions for prevention and early diagnosis that help save the lives of people we love.

"Stigma, like cancer, came into our lives with a very loud noise. When all the details of the diagnostic tests were explained to me at the first hospital where my mother was placed, I knew there was no room for error.

The first question I was asked: "Does your mother smoke?" I answered "Yes". The accusation I heard shook me as much as the cancer diagnosis."

Over the next two days, Maria moved her mother to a different hospital.

"But the stigma remained. As well as the question, "Why didn't we find it earlier? What are the gaps in the present medical system in Greece?"

Maria has nothing but the best impressions, from her interaction with the later physicians who took care of her mother, until now. She realized however that the smoking stigma is a very big barrier in the way we approach lung cancer. Stigma is also a reason why people don't get the necessary diagnostic tests done earlier when they should.

"What we need to do is support people who have been diagnosed with the disease, whether they smoked or not. As well as their beloved ones. Everyone deserves and needs our love and care. My mother is not just another patient. My dear friend is not just another lung cancer case. To me, they are everything. Why should we condemn the patient and not the disease?"

Through her story, Maria engages us in a conversation about prevention.

About screening. About early diagnosis. About doing our best in the fight against lung cancer. Whatever the cause.

So that together we can stop it before it starts.

She sends a strong message against stigma and for early diagnosis.

"Let's be part of prevention. Not of criticism."

“ What we need to do is support people who have been diagnosed with the disease, whether they smoked or not. As well as their beloved ones. Everyone deserves and needs our love and care. ”

“ For every silent tragedy of life, however, ancient drama has taught that redemption follows. I send my love and infinite support to all cancer patients who may or may not be reading this, you are admirable. You are the ones who teach us daily in this passing life the wisdom gained through similar experiences: "Check yourself, glorify hope, fight for life, pray for what is possible, be thankful, listen to everything, be kind, defend yourself from insults, cherish friendship, empathize with the unfortunate.”

**We simply don't
need fear and guilt.
We put an end to Stigma.**



Athina's story

Athina is a 53 year old mother of three children, who has deeply felt the agony of lung cancer. A few years ago, following a lung cancer diagnosis, she had surgery on her right lung. She has been living her life ever since, undergoing her regular checkups. Athina speaks about her fears, the different perspective she now has on life and the importance of psychological support. Every day, she feels the stigma through her guilt and carries it, striving for balance in her life.

"Quite as an incidental finding, in October 2019, I had to face lung cancer. I will never forget my doctor's words, when he saw the medical results: 'Athina, this is a one-way street.'"

Athina felt both shock and denial.

"I was in a panic, I couldn't accept it. I didn't want to know any details. I just wanted cancer to leave my body. To disappear. I just wanted to move on with my life. To be there for my kids."

A good friend took her by the hand and together they went to see a pulmonologist. Athina trusted her doctor and she proceeded with surgery. A third of her right lung was removed as well as her lymph nodes.

"When I woke up in the room, I saw my family behind the protective glass. They were all crying with joy. It was a great, unforgettable feeling."

A long time has passed, Athina is moving on with her life, doing her checkups and viewing things differently.

"What keeps me balanced is the psychological support I get. It's a balm to me. My therapists comfort me and rationalize my fears. I look forward to my next session. I am gradually learning to hold on to everything that matters and shed the irrelevant."

Athina smoked for many years and has recently started smoking again. However, she now feels it more as a burden and has decided to seek smoking cessation therapy.

"Lung cancer stigma associated with smoking is something I experience daily through my guilt. It is also preserved by society. It is an added burden for us all, who are struggling to cope with the disease and find balance in our lives. Within ourselves and within our family."

“ Lung cancer stigma associated with smoking is something I experience daily through my guilt. It is also preserved by society. It is an added burden for us all, who are struggling to cope with the disease and find balance in our lives.”

“ Lung cancer, often referred to as the "Invisible Cancer", is the most frequent and fatal cancer, not only in Greece but also worldwide. There is no room for attitudes that blame the patient, delay the implementation of prevention, hinder access to innovation and affect the funding of the disease. Everyone deserves a better quality of life after diagnosis. Everyone without exception deserves the same respect, the same compassion, the same care. ”

—Korina Pateli Bell,
President of FairLife L.C.C.

Early screening
gives you
the chance to live.
Time to stop the Stigma.

Eric's story



Eric, a middle school student, lost his father Simon to lung cancer at the age of 12. Simon was 57 years old and passed away, leaving his wife Korina, his 16 year old daughter Melina and his youngest son behind. Eric talks about his emotions, the injustice he feels about his loss and the importance of screening and access to clinical trials. He condemns the stigma related to smoking and the circle of guilt that afflicted both himself and his beloved father.

" In July 2019 and after a poor medical assessment for his persistent cough, my father was initially put on antibiotics and later in August he was diagnosed with lung cancer. After numerous treatments, we were told that his only hope of survival would be a new drug, only available then through a clinical trial. We had to travel to the U.S.A., unfortunately we couldn't because of the Covid 19 pandemic, time was passing and my dad's condition was getting worse. Despite our tremendous efforts, he eventually has not been able to receive the medicine in Greece and he finally passed away in August 2020. I will never forget how frustrated and angry I was. "

As Eric gets older, he tries to stay positive. But he cannot forget how much it upset him that his father, Simon, once smoked.

"My dad felt guilty about smoking, even though he had quit 12 years before he got sick. In fact, my birth was the trigger for his quitting smoking. But growing up and realizing that smoking isn't the only cause of lung cancer, I just feel sad for my past thoughts.

And if it wasn't for the stigma related to smoking, my dad wouldn't feel as though lung cancer was his own fault. And I wouldn't feel angry at him."

When Simon became ill, everything changed in the family. The burden fell on his wife Korina, who took care of him up to his very last moments.

"My sister and I are still trying to find peace and balance in our lives. It's tragic to lose a parent at such a young age. My dad didn't know about screening, which could have detected his cancer earlier and maybe even cure it."

Eric sees his father's loss as an injustice.

"I loved my father very much. He didn't deserve the stigma. He didn't deserve to miss the chance of taking part in a clinical trial, because of policy weaknesses in Greece.

And we didn't deserve to lose him, because he couldn't receive a drug that only existed at the time through a clinical trial. What should be done to ensure that all patients have access to similar studies?

“

I loved my father very much. He didn't deserve the stigma. He didn't deserve to miss the chance of taking part in a clinical trial, because of policy weaknesses in Greece.”

“

My dad had the right to know about prevention but was not given the information, he had the right to be cured but was not given the chance, he had the right to live but he just didn't get the time.”

If there was no
Stigma, you'd be
more willing
to see your doctor.

The Stigma has no place
among us.

Cynthia's story



Cynthia lost her mother Anna to Lung Cancer just a month and a half after diagnosis. There were no warning signs, until she suddenly started losing strength and needed to see her doctor. Anna's fear of screening was rooted in the stigma she carried from being a smoker. Through her brief but painful experience with lung cancer, Cynthia also felt the age stigma, which also prevents people from getting screened. She stresses that every person is special, underlines the importance of screening and the necessity of equal treatment for all patients.

"Truth is, it all happened so very quickly. I always thought cancer in the elderly progresses slowly and thus I would have time with her. I was WRONG.

I also believed that cancer gives early signs and warns early on. Here too, I was WRONG."

Anna was an educated, active person, full of life and dreams until she began to suddenly lose strength, in early December 2021. She has always been afraid of medical tests, because she had been a smoker for over 40 years and felt guilty about it.

She knew she was being criticized. She carried within her the stigma of smoking. If she hadn't felt the stigma, she would have been checked earlier, possibly diagnosed in time and have more treatment options. In addition to the stigma of smoking, Cynthia also felt the age stigma during her mother's brief journey through lung cancer. She believes it is yet one more factor which prevents people from getting screened.

"My mother was not young but she was my mum.

She was not just another patient."

Cynthia has come to understand that the stigma surrounding lung cancer marginalizes the patient.

The stigma is shutting doors. The door to screening. The door to early diagnosis. The door to equal treatment and care.

"These doors must be open. We owe it to the next patients. But also to our beloved who left us."

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These doors must be open. We owe it to the next patients. But also to our beloved who left us. ”

Challenges in the Fight against Lung Cancer in Greece and Recommendations for Required Actions

1. Increase access to prevention and screening programs

Prevention and early detection are as important as treatment, which is why they are one of the key pillars of both the National Action Plan and the European Cancer Plan.

Primary prevention includes a holistic approach to risk factors associated with cancer, such as smoking, harmful alcohol consumption, poor diet and lack of physical activity which may lead to obesity, as well as external factors, including exposure to unhealthy environmental surroundings and cancer agents.

Greece has been making every effort to reduce smoking - especially in public places, including workplaces - for more than two decades. In October 2019, the government introduced more comprehensive anti-smoking legislation as part of a new tobacco control action plan, followed by enforcement measures and sanctions. Overall, measures to reduce smoking have focused on retrospective rather than preventative policies.

An important tool in the effort to reduce smoking can be smoking cessation centres, which offer support and assistance to people who wish to quit smoking. However, the number of smoking cessation centres in Greece is quite limited in relation to the number of people who smoke. Moreover, they are not easily accessible in all areas of the country.

It is also important to consider that although new tobacco and non-tobacco products (e-cigarettes, heated tobacco products and other substitutes) are usually promoted as less harmful and as an alternative to smoking cigarettes, it is still unknown what long-term impact they may have, including their role in lung cancer development. In any case, nicotine products can be addictive. Therefore, until independent research proves their long-term safety, new tobacco products should be treated as tobacco by regulation, in order to discourage new users.³

According to the 7th European Lung Cancer Europe (LuCE) Report: "Challenges in the care pathway and preferences of people with lung cancer in Europe", which also included Greek patients, the implementation of lung cancer screening programs was identified by 64% of participants as the most useful measure for early diagnosis of the disease.¹⁰

Early detection through screening undoubtedly saves lives. However, many of the European programs which have occasionally been integrated into National Cancer Action Programs, have not been implemented and thus disparities between Member States remain.

Particularly in the case of lung cancer, early detection is crucial. When someone is diagnosed at an early stage, before symptoms appear, survival chances are very good. When someone is diagnosed at a later stage, survival chances are significantly reduced, since there are fewer options for effective treatment.

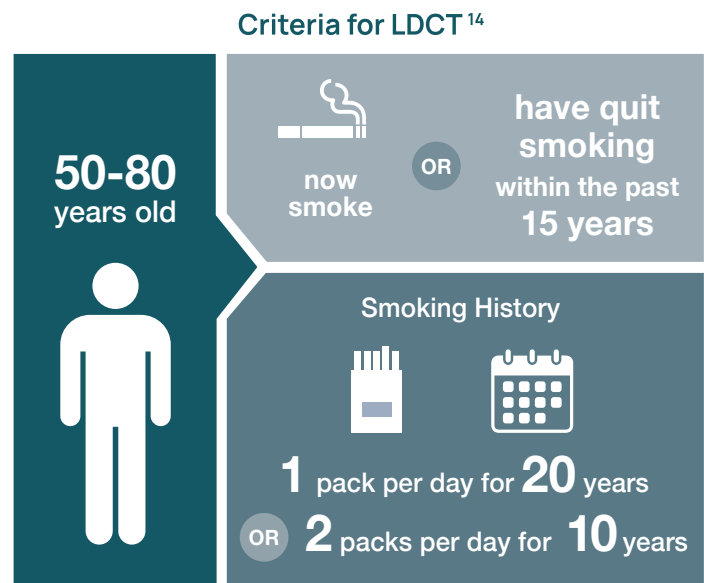
The percentage of lung cancer detected at stage 1 and 2 in Greece, in 2019, is 17% (a very low rate compared to e.g. the UK, where the rate is 24%-28%), while in the midst of the pandemic, new lung cancer cases in general have been reported to decrease by 38%, compared to 2019. This is an indication that patients are now seeing their doctors (for screening or after the onset of symptoms) at a very late stage.^{11,12}

Early detection is facilitated by screening programs.

Screening of high-risk individuals with low-dose computed tomography (LDCT) is associated with a 20-25% reduction in lung cancer mortality. These programs are inexpensive, save lives and spare vital healthcare resources, which would otherwise be spent on treating advanced cancer.¹³

Taking into account the preliminary evidence on screening, using low-dose computed tomography and the necessity of a gradual approach, Greece should consider the feasibility and effectiveness of this program through primary and secondary prevention implementation studies, initially targeting high-risk individuals with the aim of reducing lung cancer risk.

Additional attention should be paid to identifying and targeting further individuals with a high-risk profile.



2. Expand access to molecular testing and innovative targeted therapies

Timely access to new cancer treatments and better availability of targeted drugs are of high importance for cancer patients, yet in Greece patients often need to wait for a long time to receive newly approved reimbursed and innovative drugs. In 2017, time to market for innovative oncology medicines in Greece (e.g. immunotherapy or targeted therapy) exceeded the European Union average and this situation has only worsened over time.

One of the major discoveries in lung cancer treatment is that lung cancer is not a single disease, but rather comprises a family of diseases - each with its own molecular-genetic variations. The identification of these variants may open up new possibilities to treat and cure cancer in the form of targeted therapies.

Targeted therapies fight cancer cells through interaction with specific molecules, essential for their survival and reproduction. On the other hand, traditional therapies, such as chemotherapy, are not directed at certain molecular targets and tend to attack healthy cells as well. In addition to curing or increasing life expectancy, targeted therapies may mean reduced side effects and a better quality of life for lung cancer patients.

The first step on the road to targeted therapies is molecular testing of a tumor's sample tissue, also known as biomarker testing.

However, patients face problems regarding precision oncology medication which require biomarker testing; many of these tests are either not available or not reimbursed in Greece or doctors are not informed about reimbursement schemes. The government should develop a national framework of molecular testing to facilitate access for people with lung cancer, in line with European guidelines.

A key component of high quality and personalized lung cancer care is the interdisciplinary tumor board, yet it is not universally available in all clinical/hospital settings. Management of lung cancer by a multidisciplinary team has been shown to facilitate faster and more accurate diagnosis, better access to appropriate treatment, improved coordination and quality of care, and longer survival. The formation of an oncology board to determine lung cancer patients' treatment should be mandatory in public and private hospitals.

Clinical trials are the pillar for the development of new innovative therapies, which, in addition to benefits for patients, also support the national economy. Unfortunately, Greece lags significantly behind in the number of clinical trials.¹⁵ In terms of pharmaceutical R&D investment, Hungary is 5 times, Denmark 30 times and Belgium 70 times more attractive than Greece.¹⁶ Apart from financial implications, Greece's underperformance also means limited access of Greek patients to clinical trials. Thus, the benefits of clinical trials for patients, including rapid access to new treatments, cost-free medication, laboratory and diagnostic tests as well as ongoing

and high-quality medical monitoring, remain largely untapped in Greece. The European Regulation 536/2014 (EU-CTR) on clinical trials, which came into force on January 1st, 2022, creates the framework for increased transparency but also for the emergence of new opportunities for patient participation. The proposal of the Hellenic Association of Pharmaceutical Companies (SFEE) to build an Executive Structure at the Ministry of Health, modeled on the Danish National Clinical Trials Office (which was established in 2012 and has delivered significant results), is an important step towards developing a long-term strategy for coordinating and attracting resources for clinical trials in Greece.

3. Improve access to psychosocial support services

Lung cancer is a very heavy burden for people impacted by the disease. Patients, caregivers and families may experience fear, anxiety, stress and depression. Suffering new symptoms, cancer spreading and side effects from treatment can make it all even harder to endure.

Feelings and concerns may change depending on the age of the individual or the cancer stage.

For instance, those diagnosed younger have to cope with the disease, while raising families and building careers. For older adults, medical issues related to aging may be occurring at the same time with lung cancer. Other patients may struggle with end-of-life care and symptom management.

Providing mental health care and social support can minimize stress, improve quality of life, address depression and/or anxiety, and improve coping skills. It may include training and peer support, as well as services from social workers and counselors, psychologists and psychiatrists.

Not all lung cancer patients are offered the opportunity to receive mental health care and social support together with medical treatment.

Sadly, some people avoid seeking help for fear of being condemned because of the stigma associated with lung cancer.

People diagnosed with lung cancer should be screened for anxiety with a clinically validated tool. Individuals experiencing distress should be referred for additional care as needed.

In the past decade, changes in both the disease pattern and the social and economic environment have made the need for long-term care structures more important than ever. It should be noted that the field of long-term care, as that of prevention, is deficient both in terms of personnel, expertise and funding compared to care structures in Greece.

Access to psychological services, which may include counseling, psychotherapy and support in monitoring the disease, is essential. The same applies to the provision of social support, which can also improve the quality of life of people with lung cancer and their families. Social support can include counseling, support in managing financial difficulties, help in finding community support services and assistance in the transition from therapy to rehabilitation.

Appropriate information and education of health professionals is key to improving support for patients and their families. Educating doctors, nurses and other health professionals about how to address the psychological and social needs of people with lung cancer is important to improve the provision of psychological and social support services. In addition, collaboration between different disciplines, such as oncologists, psychiatrists and social workers, can help to identify and address the psychological and social needs of people with lung cancer and their families.

Support for patient associations is also important, as they can provide valuable assistance to people with lung cancer, caregivers and families, offering services, including conversation groups, information and advice.

4. Establish information and awareness around lung cancer

People are often unaware that some symptoms can be indicative of lung cancer and are late in seeking medical advice.

Many people may think of lung cancer as a disease that cannot be treated. They are probably unaware of all treatment options available or do not realize the importance of early diagnosis. The above information gaps are particularly prevalent among people from socioeconomically underprivileged groups and could pose additional barriers to appropriate diagnosis and care.

In addition to delayed diagnosis, insufficient information has been shown to affect participation in lung cancer screening programs.

Furthermore, patients do not receive or comprehend all the information required for consent to their treatment and optimal cooperation with their healthcare team.

A coordinated effort is necessary from various bodies and organizations to fill the gap in lung cancer information, ranging from advertisements in the media and social media to distribution of informative material and awareness activities in communities and schools. Raising the issue of lung cancer in the public discussion is key to raising awareness. In addition, patient associations can provide support and information to patients and their families as well as organize meetings and activities to promote knowledge and awareness. Health professionals, workshops and conferences may be offered the opportunity to learn more about lung cancer and the latest developments, regarding prevention and treatment, through workshops and conferences.

5. Integrate palliative and hospice care into healthcare services

Greece has not yet established an organized framework for palliative care services, especially for home-based services. This issue has not been widely discussed, especially among policy makers, although efforts have been made in the past to build such a framework.

Greece is a country with very limited palliative and hospice care services, provided mainly on a voluntary basis, within public hospitals, by nurses paid by families on an hourly basis, by unqualified home care workers (usually migrant women) or by private providers, non-profit organizations and charity foundations. As a result, households and families face significant financial burdens, both directly, when covering the cost of care, and indirectly, when family members suffer a loss of income to care for family members.

A study involving patients with terminal lung cancer, who passed away between September 2011 and June 2014,¹⁷ showed that direct medical costs in the final six months of their lives were significant. In particular, around 74% of total inpatient care costs were associated with chemotherapy, suggesting a significant lack of financial protection, which is an element of comprehensive health coverage. Other inpatient care costs included hospitalization (17%), hospital charges (8%) and transfusions (1%). The highest outpatient care costs were associated with co-administered medication (59%), followed by the costs of tests (21%) and radiotherapy (20%). In addition, the costs of both inpatient and outpatient services during that period showed an increasing pattern, culminating in the fifth month, which suggested the implementation of a less intensive treatment scheme in the last month of life.

The National Public Health Action Plan 2021-2025 identified the need to develop a national strategy for palliative care and highlighted the importance of integrating palliative care into health care services, while specific actions remain to be defined. Very recently, a legislative act was voted by the Greek Parliament, aiming to establish a framework for the development of palliative care services.



So, let's stop asking the wrong question "Did you smoke?" Let's start asking the right questions, and shape together more effective ways to promote lung cancer prevention and early diagnosis. To support patients and their caregivers, so as to ensure timely and accurate diagnosis, comprehensive and reliable information, personalized treatment, access to clinical trials, and all the care and support they need and deserve."

"The battle that however hard we tried, we could not unfortunately win. The hardest part of being diagnosed with an inoperable cancer is not what I'm going through, but seeing how much my family is suffering. ,,"

—Simon Bell

FairLife – Lung Cancer Care was founded in memory of Simon Bell, 57, who lost the battle with lung cancer in August 2020.

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