

European Lung Foundation submission to the European Commission's call for evidence on mental health: "A comprehensive approach to mental health"

The European Lung Foundation (ELF), a patient-led organisation that brings together lung patients, health professionals and the public, appreciates the opportunity to input into the call for evidence on a comprehensive approach to mental health. We completely support the efforts of the European Commission to promote good mental health, and to prevent, mitigate and respond to mental health challenges, as well as its intention to factor mental health considerations into a wide variety of resilient EU and national policies. Given this opportunity, we aim to provide an insight into the interconnectivity of mental health and lung conditions. We hope that our contribution will shed light on the psychological needs of people with respiratory diseases.

Our response has been put together using a number of sources, along with the testimonials of people living with lung conditions, with whom we have been working closely to hold workshops, meaningful discussions and produce videos about their lived experience.

Mental health is as important as physical health and one impacts the other¹, not only in everyday life, but especially during treatment and/or recovery from disease². People who live with lung conditions are likely to experience issues with their mental health and well-being. This can be due to several factors including: difficulty carrying out daily activities, concerns about being breathless (some individuals with a lung condition may avoid exercising, or walking, as they fear running out of breath), or general concern about their lung condition³.

Individuals also have concerns about taking medication, due to some of the impacts (e.g. steroids and weight gain), while others need to regularly take antibiotics to fight infections. Finally, many patients avoid socialising due to symptoms and visible presentations of disease (e.g. coughing, cyanosis), leading to a feeling of isolation⁴. Feeling that symptoms are out of control can lead to poorer mental well-being. This could result in a vicious circle and in deterioration of a person's quality of life.

From our Patient Advisory Groups⁵ we have gathered multiple testimonials from people with different lung conditions, such as severe asthma, long-COVID, lung cancer, pulmonary fibrosis and pulmonary hypertension. Our Patient Advisory Groups have told us how their conditions have affected their everyday lives, their experiences with healthcare services and facilities, and the way these factors affect them mentally.

Their testimonials include the difficulty in getting out and socialising, the lack of a support system at work that could help them be more comfortable and the lack of sufficient national healthcare that has – in some cases – led to people moving to a different country because of a lack of health security and proper facilities as well as mental rehabilitation. Furthermore, they deal with personal feelings and emotions, the perception of them and their condition by the people around them and the difficulty in finding others with similar experiences.

¹ <https://www.tandfonline.com/doi/full/10.1080/09638237.2021.1898552>

<https://healthcare.utah.edu/healthfeed/postings/2022/04/mental-health-is-physical-health.php>

² <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2835700/>

³ <https://breathe.ersjournals.com/content/16/2/162ELF>

⁴ <https://breathe.ersjournals.com/content/16/2/162ELF>

⁵ <https://europeanlung.org/en/get-involved/join-patient-advisory-group/>

Some individuals have also mentioned that they could feel alone if the medics aren't hearing their voice. This can be demoralising, because it can make someone feel that there is no point in seeing their medic because they don't care/listen. Furthermore, other testimonials include the experience of big mood swings because of medication, such as steroids; thoughts about death during a sudden crisis, such as a severe asthma attack, as well as avoiding discussions about mental health, so that others won't mistake the lung condition symptoms for stress (e.g. a person who cannot breathe properly because they have an asthma attack doesn't want others to think that the breathlessness was because of stress). Some parents say that their teenage children are ashamed of visual changes due to minimal physical activity.

Moreover, many patients are dependent on devices and machines, and they require respiratory support through oxygen supplementation flow. This sometimes may be needed all day, every day. In other cases, patients may need to use an oxygen concentrator or ventilators during the night and sometimes during the day. It is often felt that these aids are difficult to manage especially during the first phase of initiation and getting used to their functioning. Patients may experience feelings of depression and increased anxiety because they rely on a machine to continue breathing efficiently. This vicious circle triggers further feelings of social isolation and unsafety for both patients and caregivers.

In order to make more visible the mental health experiences of people with lung conditions and to tackle the impact on their everyday lives, ELF proposes the following set of objectives and priorities:

- **Mental health services should be accessible to everyone.** Mental health services tend to be difficult to access, with long waiting times. This affects us all, but some groups are more affected than others. People with disabilities, people who live in remote areas, the elderly, children and adolescents, people with financial difficulties, immigrants, those who don't have access to the internet, as well as those who - for any reason - have difficulty in travelling, do not always have access to mental health specialists. Also, due to low medical literacy some patients are shy or not able to ask for help and support. As a result, they might not have the opportunity to get support. Member states could develop more e-services for people who cannot physically reach a specialist's office, they could develop a network of specialists that are available to consult in different languages, they could provide free services to groups of people who live below the poverty line, and they could provide incentives to specialists who decide to leave big cities to work in smaller/rural areas.
- **Providing support to people with mental health issues in the workplace, at school and at university.** Sometimes a mental health issue can make the everyday life of the person who has it more complicated. If at the same time their health is affected by a physical condition that might require regular visits to doctors and/or the use of medical equipment (such as oxygen, inhalers, injections, etc.), the assistance of a mental health specialist could be beneficial. It could help them not only to better integrate, socialise and feel more comfortable, but also to develop their capabilities, skills, and productivity to the fullest. For this reason, mental healthcare specialists and/or caregivers could be appointed.
- **Empowerment of the voices of people who face health issues.** Quite often, patients feel that they are alone in facing their health issues, either because they are not in contact with other people who face the same health problem, or because the general public isn't familiar with their condition. This could result in isolation, loneliness, and an inability to have a sense of belonging, which could affect their mental health. For this reason, it is important that the EU and member states organise informational campaigns that would raise awareness and reduce stigma, for TV, social media, and schools. Furthermore, they could promote the creation of patient groups, so that people who face the same or similar health issues can build a strong

network of emotional and practical support. These groups could also support patients in improving self-management, which could lead to improving their mental health. Furthermore, patient conferences could be organised, aiming at giving patients the chance to discuss and learn more about their conditions. This would empower them and could improve their mental well-being.

- **Improving healthcare facilities.** Over the last few years, our society has been very challenged by the COVID-19 crisis, which really tested our healthcare systems and our preparedness. On the other hand, COVID-19 made more understood the everyday life of some respiratory patients, who feel that the general public understands better now what it is like to live with a chronic lung condition. COVID-19 highlighted the psychological aspect of a disease for the general public, since many people felt isolated, changed their everyday habits, started working from home more, took more prevention measures than usual (masks, hand sanitizers, avoiding crowded places, etc.). This could be seen as an incentive not only to focus more on the psychological aspect of a disease, but also increase and ameliorate healthcare services and facilities in general. This way, people would increase their general trust to healthcare providers, and they would feel more secure to talk about the mental aspect of their condition.
- Another important factor that should be taken into consideration is the **interinstitutional and interdisciplinary cooperation**. It is of utmost importance to take into consideration all of a patient's needs and medical history, so that a specialist/doctor will get a more holistic idea of the factors that affect the overall lung condition and mental health of the patient. To achieve this, member states could create coordinating bodies that could facilitate communication and cooperation among different specialists and institutions.
- The promotion of **lifelong learning** is very important to keep doctors, psychologists and social workers updated about all the advancements that could help improve the lives of the people who need treatment. Science and technology are advancing fast, providing new treatments and solutions that could change the lives of many people. For that reason, it is important to allocate more funding in programmes such as Erasmus plus, that can give professionals opportunities to better research the link between respiratory and mental health, to exchange expertise and good practices and to participate in life learning programmes not only in Europe but also in the rest of the world.
- **Mental support to caregivers.** Taking care of a person who has health issues can be challenging not only for that person, but also for their family and care providers. In order for them to give their best possible support, but also to discuss the challenges they are facing, caregivers should also have easy and affordable access to mental health services. Furthermore, providing them with educational programmes on mental and physical needs could also be beneficial for both sides and it could alleviate stress, since the management of the symptoms could be under more control and people would be able to intervene and help in case of an emergency.
- **Mental health should be integrated into all EU policies.** Mental health is affected by many aspects that have to do not only with personal and genetic factors, but also with poverty, education, big social changes, discrimination, injustice, environment, economy, etc. We believe that an effective way to approach mental health would be to revise the EU policies to make sure that mental health is included in a way that fairness, social inclusion and advancement are taken into consideration, and no one is left behind.