

EoE: The hidden treatable disease that requires a visible policy response

CO-DEVELOPED BY

Apfed American Partnership for Eosinophilic Disorders

EOSNETWORK Eosinophilic Diseases Charity

GLOBAL ALLERGY & AIRWAYS PATIENT PLATFORM

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Executive Summary

Eosinophilic esophagitis (EoE) is a chronic, life-impacting Type 2 inflammatory disease that can be progressive and is usually triggered by food or allergens.

Exploring the impact and challenges of living with EoE

EoE is initially characterized by swallowing difficulties, vomiting, abdominal pain and acid reflux that doesn't respond to medication.

It is also a disease which changes as people age, not only through the significant variations in clinical and mental health impact of the disease, but also through acute and chronic complications, which can progress to more severe forms of EoE, if left untreated.

People living with EoE face significant barriers to timely diagnosis, which can jeopardize and prevent the early intervention that is essential to alleviate symptoms and control disease progression. **These challenges are compounded by an increased risk of related comorbidities, with 25% of EoE patients also suffering from asthma, 23% from allergic rhinitis, and over two-thirds from gastroesophageal reflux disease (GERD)** [3]. The overlap of symptoms can lead to further delays in EoE diagnosis ranging from 4 to 11 years [4], and the coexistence of these conditions can exacerbate EoE and its complications [5] [4].

Even upon diagnosis, **the lifelong treatment of EoE to prevent relapse and slow progression presents further hurdles**, driven by inconsistent access to specialists, limitations in disease monitoring, and a lack of multidisciplinary care – including mental health support.

Up to a third of patients experience anxiety and depression due to challenges in disease management, self-perception issues, delayed diagnosis, and misdiagnosis, coupled with difficulties in accessing psychological support and achieving alignment among healthcare professionals [6] [7]. Additionally, **EoE negatively impacts caregivers' mental health as they adjust their lives to support affected children** [9].

Moving beyond the clinical element, EoE also impacts patients and caregivers on an **emotional, practical, and economic level.** The need for restrictive diets and repeated procedures (such as endoscopy with biopsies) may affect quality of life and lead to social withdrawal and anxiety [11].

Furthermore, EoE places a substantial **financial burden on patients and caregivers due to costly treatments and limited access to approved medications**, leading to out-of-pocket payment for private healthcare and, in some cases, off-label medications [12] [13]. This cost is also felt on the side of the healthcare system, with EoE management cost exceeding that of other conditions like inflammatory bowel disease (IBD) and celiac disease [14] [15].

Why a position paper on EoE

The ultimate objective of this position paper is to achieve a more supportive policy environment for patients



Eosinophilic esophagitis (EoE) has long been an afterthought in the modern care landscape – but that cannot continue. It is time to reduce the diagnostic timeline. It is time to address equitable access to innovation. It is time to provide alternative options to patients struggling with high disease burden and low quality of life.

Easily overlooked or misdiagnosed, EoE is a chronic, life-impacting disease that can be progressive and is caused by an inflammatory response in the esophagus. If left undiagnosed, EoE – which can present initially as a difficulty swallowing (dysphagia), vomiting, or abdominal pain [16] – may progress to an advanced form of the disease, characterized by a severe narrowing of the esophagus and fibrosis. Additionally, an increase in prevalence has been seen over the past three decades [16] with a four-fold increase over the last ten years [17].

The ultimate objective of this position paper is to achieve a more supportive policy environment for patients; one which considers the cumulative burden and challenges of the disease – at the individual and societal levels – and seeks to address these by providing patients and their caregivers with access to treatment and holistic, long-term care, enabling them to better manage their condition for the benefit of all.

Developed with advocates, patients and healthcare professionals, the **policy recommendations** in this paper call for better and more consistent recognition, prioritization, and management of EoE.

These recommendations can help foster better health outcomes for patients, caregivers and society at large.

An urgent need for action

With global incidence on the rise [18], there is an increasingly urgent need to act to reduce diagnostic delays, ensure equitable access to innovative treatments, and provide relief for those living with the life-altering impact of EoE.

This position paper, created in collaboration with advocates, patients, and healthcare professionals, calls for the creation of a more supportive policy environment. The full cumulative burden of EoE on individuals and society must be recognized to ensure access to comprehensive treatment and holistic, long-term care. As such, we urge policymakers to prioritize EoE, fostering better recognition, management, and outcomes for patients and caregivers alike.



Recommendations for better and more consistent care

Recognize EoE as a serious chronic disease and public health priority by:

- Calling on the European Parliament and national governments to **develop and commit to action plans** to ensure access to quality healthcare services for people living with severe digestive diseases and Type 2 inflammatory conditions such as EoE
- Using the upcoming UN High Level Meeting on Non-Communicable Diseases' political declaration as a springboard to achieve **recognition for the mental health burden which Type 2 inflammatory conditions, such as EoE, place on individuals and their caregivers**

Enable timely and accurate diagnosis of EoE to prevent long-term damage to patients and cumulative burden to individuals and healthcare systems by:

- Investing in **training for healthcare professionals**, particularly in primary care and emergency care, to help **identify the signs and symptoms** of EoE as well as **adaptive behaviors** in a comprehensive way and **ensure timely and appropriate referrals**
- Establishing **effective diagnostic pathways** to ensure early detection and effective management of EoE and comorbidities
- Unlocking **funding and incentives for research into and development of non-invasive biomarkers** (e.g. blood markers, string tests) and **AI imaging for biopsies** for diagnosis and monitoring, and looking at how they could be implemented in the healthcare system

Improve long term health outcomes through the implementation of integrated, multi-disciplinary care for EoE by:

- **Standardizing coordinated care of EoE patients**, involving gastroenterologists, expert dieticians, allergists, immunologists, dermatologists, pulmonologists, ENTs and psychologists
- Creating **EoE-specific guidelines** for a smooth **transition from pediatric to adult care**, ensuring patients benefit from continued care

Prioritize patient access to the right treatment at the right time, including advanced therapies, to control disease impact and reduce burden and relapses by:

- Ensuring patients have **access to a wide range of treatments, including innovative targeted therapies** such as biologics
- Empowering patients to be better informed through **education and shared decision-making** regarding **treatments** that align with international clinical guidelines to better reflect the concerns, needs and preferences of the patients **so they may better adhere to the prescribed treatment plan**
- Supporting **long-term monitoring of disease evolution** and adjustments to treatment approaches through **continued access and reimbursement of diagnostics** (e.g. biopsy, endoscopy)
- **Removing barriers** to HCPs **prescribing the right therapy** for the right patient at the right time

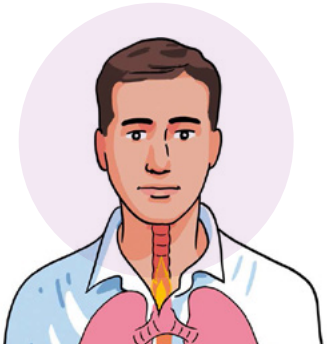
Fund the collection of real-world evidence and research to better capture the unmet need by:

- Establishing **real-world registries** that can support better and more consistent care, including treatment selection and personalized care
- Improving **understanding** of the **cost-offset of different treatments** for healthcare systems and out-of-pocket costs for patients
- **Funding collaborative research projects** to mitigate current **data gaps** and support healthcare **decision-making**, as well as improve **health equity** at a global level. These would include, but are not limited to, disease progression, the direct and indirect impact of EoE on quality of life and mental health, the impact of progression and relapsing on patients and direct and indirect costs for individuals and healthcare systems

Challenges faced by EoE patients

What is EoE?

A Type 2 inflammatory, progressive disease



Triggered by a reaction to food or aeroallergens [19] [20], eosinophilic esophagitis (EoE) is **a chronic, life-impacting disease** affecting the esophagus, which may progress to more severe forms of disease and to relapses when left untreated.

EoE symptoms are associated with an immune response known as Type 2 inflammation (T2i), in which T cells are triggered [21] and cause swelling in the esophagus [22]. **What initially presents as difficulty swallowing, vomiting, abdominal pain and acid reflux that doesn't respond to medication, may lead to acute complications** such as dysphagia, motility issues, fatigue and food impaction; as well as chronic complications such as fibrosis and progressive structural and functional damage to the esophagus [23] [24]. Long-term fibrosis increases tissue remodeling and stiffness leading to **food obstructing the esophagus resulting in being unable to swallow water or saliva, and commonly requires emergency care** [25] [23] [26] [27].



Studies show a **9% increased risk** in esophageal strictures and narrowing for **each year** of undiagnosed EoE, with strictures present in 52% of patients after 21 years without diagnosis. [25]

Despite a rapid increase in incidence and prevalence in recent years, the etiology and pathophysiology of the disease remain unknown – studies suggest a link to complex interactions between environmental factors, genetic and epigenetic changes [23] [18] [29]. The disease is commonly encountered in gastroenterology and allergy practices, emergency departments, and primary care settings [24]. **Low awareness of EoE symptoms, a lack of coordination across primary care and specialist settings and long waiting times for appointments with specialists can lead to delays in diagnosis and treatment initiation.** This delayed diagnosis has been seen to trigger so-called adaptive behaviors from patients that add an additional layer of complexity in diagnosing what is seen as a silent disease. Yet, **early diagnosis and timely intervention are vital** to maintain the disease in its earlier stages and safeguard quality of life for patients.

The diagnosis of EoE relies on both symptoms and tissue findings, **as no single feature is specific to EoE** [20]. Once an assessment of symptoms has been made, the patient undergoes an upper endoscopy (visual) and biopsies where six tissue samples will be taken from different parts of the esophagus to avoid patchiness of the disease [20]. The treating physician should exclude other conditions such as infections or other inflammatory diseases [30]. Non-invasive tests (e.g. esophageal string test, molecular panels) and advanced imaging are under investigation but are not yet standard practice [31].

Furthermore, patients will require **continuous treatment and monitoring over their lifetime to help spot disease recurrence and in turn reduce the risk of a relapse and complications**, the mere notion of which can cause **severe mental health strain**.

52.95 / 100,000

32.9 / 100,000

Since 1976, the **prevalence of EoE has been steadily increasing globally**, from 8.18 cases per 100,000 inhabitant-years in the 1976-2001 period to 74.42 cases per 100,000 inhabitant-years in the 2017-2022.

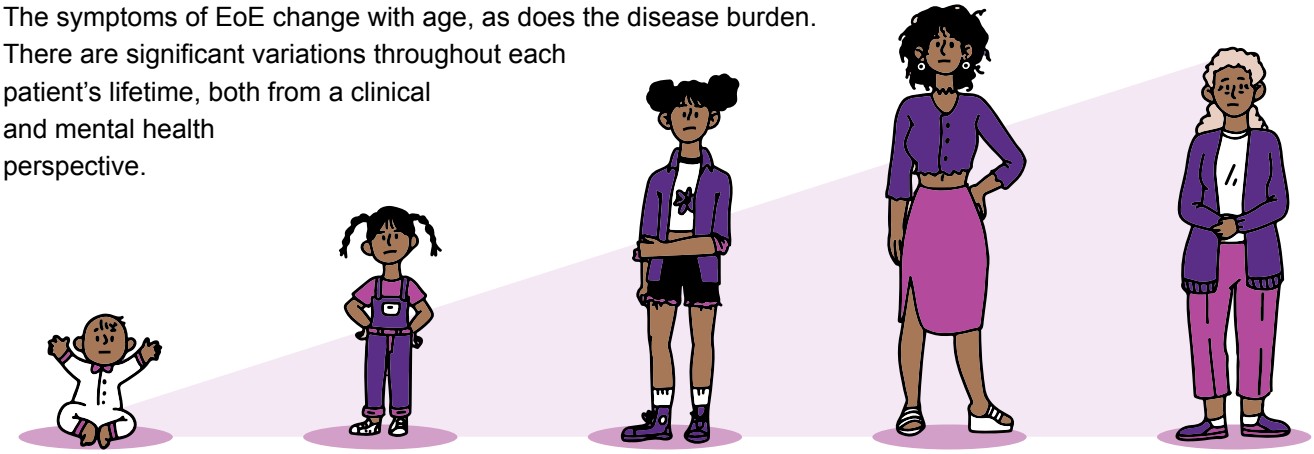
Prevalence is higher in adults (52.95/100,000) **than in children** (32.9/100,000).

It also varies across the world, with higher prevalence in North America than in Europe. However, further research is needed in Asia, South America and Africa.

[50]

EoE evolves over a person's lifetime

The symptoms of EoE change with age, as does the disease burden. There are significant variations throughout each patient's lifetime, both from a clinical and mental health perspective.



Infant patients

Struggle with symptoms not specific to the disease, like gagging, food refusal [21] and delayed introduction of solid food – leading to failure to thrive [21] [32] in extreme cases [33] [34].

Childhood patients

Develop vomiting [65], which can be a debilitating symptom [35] impacting nearly 60% of pediatric patients [21], start experiencing dysphagia [20].

Teenage patients

More likely to have food obstructions and dysphagia [65], as well as non-cardiac chest pains, which can be quite incapacitating [32].

Adult patients

Face incapacitating symptoms such as dysphagia and food impaction [32].

Older adult patients

Are prone to more esophageal strictures, which contribute to narrowing of the esophagus making swallowing more difficult and increasing the risk of choking [21].

The progressive nature of the disease is also highlighted through the degree of endoscopic fibrosis in undiagnosed patients, with delayed diagnosis increasing fibrosis. A study in the Netherlands showed that while 39% undiagnosed children demonstrated fibrosis, the figure rose to 76% in adult participants [6].



"The chronic nature of EoE means that patients face mental health challenges at each stage of their life with symptoms ranging from an aversion to food and bullying in childhood, strained relationships and trust or secrecy issues with parents and caregivers during teenage years due to highly restrictive food diets, social impairment as adults driven by complex dietary needs or fear of food obstruction, related anxiety and isolation. This is a significant challenge that is not being sufficiently addressed with implications on adherence to treatment protocols, disease progression, the frequency of relapses and people's quality of daily life."



AMANDA CORDELL
CEO and Founder, EOS Network

EoE is associated with an increased risk of comorbidities

EoE shares pathophysiological pathways with other T2i diseases such as asthma, atopic dermatitis, and allergic rhinitis [1] [36]. Because of this, **people living with EoE are at an increased risk of related comorbidities**, with 25% of patients also suffering from asthma and 23% from allergic rhinitis [2].

In addition, over two thirds of EoE patients also suffer from GERD [3]. The overlap of symptoms can lead to a delayed EoE diagnosis, and the coexistence of both diseases can facilitate EoE and its complications [5]. The degree and nature of this interaction likely vary among individuals and may be influenced by factors such as age and genetic predisposition [37].

Lastly, it is important to underline the impact EoE has on a patient's mental health, with **up to a third of patients reporting that they experience regular anxiety and depression** [6] [7]. This is driven by factors such as the day-to-day management of the disease, the impact on a person's perception of themselves and external factors including delayed diagnosis, misdiagnosis, anxiety stemming from a lack of alignment across healthcare professionals or challenges accessing the right medical professionals and finding the right psychological support [8].



The broader impact of comorbidities can be quantified through the increase in the number of medications patients need to manage at an individual level and on their overall consumption of healthcare services at a societal level.

Aside from the increased cost, **additional medications** also expose patients to a greater risk of potential side effects, bring additional challenges around adherence to treatment and finally increas the overall psychological burden of the disease [1].

What are the main challenges that patients face along their care journey?

A challenging path to diagnosis

Diagnosing EoE presents several challenges that impact the timely and effective treatment of the disease, ranging from the reliance patients have on adaptive behaviors, all the way to structural or systemic issues. Each of these factors contributes to a complex diagnostic landscape that hinders early intervention and effective management of EoE.

Adaptive behaviours include

I Imbibe fluids
M Modify foods
P Prolong meal times
A Avoid heard texture foods
C Chew excessively
T Turn away tablets/pills
S Social impairment

[38] [39]

Spotlight on Europe

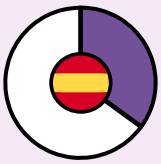
In **Europe**, a study of nearly 700 EoE patients found a mean delay of 10.1 months from symptom onset to first healthcare consultation at a mean age of 30.5, followed by an additional 7.1 months until diagnosis at a mean age of 32.7 [2].

For children, average diagnostic delays extend to seven years due to the non-specific nature of early symptoms. A Swiss study highlighted that only 47% of patients diagnosed within two years developed esophageal strictures, compared to 88% diagnosed after 20 years of symptoms [6].

Initial diagnosis barriers: Primary care physicians (PCPs) will often be the first interaction patients have with the healthcare system. However, the **overlap between EoE symptoms and other chronic conditions [5] leads to delays in diagnosis ranging from 4 to 11 years** [4]. Among children, the median diagnostic delay is shorter (1.2 years), though young children (under 6 years old) experience longer delays due to non-specific symptoms [65]. This issue is compounded by patients changing their eating behaviors to avoid symptoms [6] – inadvertently masking the disease. This means that PCPs need to be diligent in identifying adaptive behaviors and be prepared to ask questions in a way that helps patients provide more substantive answers and can uncover hidden symptoms. Pediatricians must stay particularly vigilant as younger patients may have trouble expressing their symptoms due to developing language skills.

Referral and access issues: Once diagnosed, as many as 86% of patients report having been referred to several gastroenterologists before receiving the correct diagnosis [9]. EoE's difficult-to-diagnose nature **often results in misdiagnoses** by healthcare professionals (HCPs) when they see symptoms related to **psychological causes, like eating disorders or other conditions,** or when physicians are confounded by the symptoms and instead link those to anxiety attacks, **further delaying gastroenterologist referrals** [9]. Patients outside

Spotlight on Spain



2-5 years
for final diagnosis

In **Spain**, a study of patients with multiple T2i diseases (comorbid with EoE), found that 35% of patients obtained a final diagnosis of one of their T2i diseases after two or more than five years, while 63% of patients had visited more than three specialists since the onset of their disease [46] [47].

metropolitan hubs, in rural areas or facing reduced access to healthcare due to affordability or social issues face even greater hurdles.

Perception and stigma: Patient perception plays a crucial role in diagnosis delays. Many patients **fail to recognize their symptoms as indicative of a disease** and instead adopt **adaptive strategies** to manage them, allowing the disease to progress unchecked [9]. Additionally, the stigma associated with discussing such symptoms leads some patients to delay seeking treatment [41].

Emotional and psychological impact: : During the early stages of the disease, patients may experience **worry, fear, anxiety, and frustration** due to the lack of EoE awareness, its impact on quality of life, and the arduous diagnostic process [9].

Differences across regions: Access to diagnosis and treatment for EoE also varies from country to country. In areas with more developed healthcare resources, people tend to have faster access to medical services, while **those in less equipped regions** often encounter longer delays. Delays in seeking help for symptoms can occur when patients do not perceive their symptoms as serious, whereas strong monitoring systems in some countries promote faster diagnosis and treatment. Furthermore, in regions where health literacy and patient education levels are greater, patients and their families may be faster at identifying the clues to diagnosis.

Impact of diagnostic delays: Ultimately, delays in diagnosis jeopardize and prevent the early intervention that is essential to alleviate symptoms and control disease progression. **The culmination of these diagnostic hurdles can nearly double the degree of endoscopic fibrosis seen in patients**, reflecting the severe consequences of misdiagnosis and delayed treatment [9]. Understanding and addressing these delays is critical for improving the patient journey and outcomes in EoE management.

Limitations in the way EoE is currently assessed, monitored and treated

Effective patient follow-up and monitoring is significantly impacted by limitations in current EoE assessment and monitoring practices. **Relying on invasive procedures like endoscopies and biopsies means that patients potentially face a range of issues**, including frequent sampling errors, biomarker limitations, a disconnect between symptoms and histology, imaging limitations and disease heterogeneity [6] [38] [42]. This invasive approach not only carries costs and procedural risks but also adds a substantial burden to patients, with a need for repeated procedures and regular follow-up [32].

Human error in the histopathological review of EoE patient samples is a recognized concern, with multiple potential sources of variability and diagnostic pitfalls. For instance, while endoscopic scoring systems help standardize assessment [43], **a lack of appropriate imaging tools means subtle disease progression is potentially missed** [44], pushing diagnosis or acceleration of treatment to a later stage [45] [32]. While manual pathology remains the gold standard, efforts to standardize criteria and implement automated digital analysis are promising steps toward minimizing errors and improving patient care.

A **gap in care** is defined as an EoE patient not benefiting from medical contact for more than two years [46]. While there are various reasons for this, including

a lack of annual follow up from HCPs [27] – despite medical guidelines recommending this – **relapsing can be significant** [6]. In a retrospective cohort study of over 700 patients, 14% experienced a gap in care and presented with food impaction requiring emergency intervention, higher endoscopic severity and greater narrowing of the esophagus [46].

There is a need for **validated, non-invasive biomarkers** and more **holistic, patient-centered assessment tools** to improve disease management and reduce the burden on patients [1] [32].

From a treatment perspective, the current standard of care also comes with challenging side effects, including an increased rate of adverse events (dilation, infections, upper respiratory tract infections, skin disorders) linked to repeated, long-term use of topical corticosteroids (TCS) [47]. Furthermore, there remains limited data regarding maintenance of long-term remission [21]. Challenges also exist around administration if compounding the medication is required.



"In Germany, while diagnosis of EoE is often delayed, initial access to treatment isn't the problem. Issues arise when healthcare professionals are unfamiliar with the need for long-term management of EoE. Despite guideline recommendations, we often find that patients receive 12 weeks of treatment but then are 'lost' at the follow-up stage. This is where our attention is needed, to make sure patients don't fall into this gap and achieve sustained control."

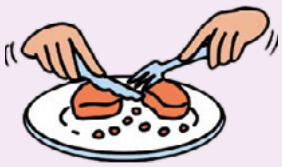


PROF. DR. MED. HABIL. AHMED MADISCH
Chief Physician, DIAKOVERE Friederikenstift (Germany)

Limitations in the transition between pediatric and adolescent or adult care

Transition care refers to the process of moving adolescents and young adults with chronic diseases like EoE from pediatric to adult healthcare services. This period is critical for ensuring continuity of care and long-term disease management, but it presents several unique challenges for EoE patients. The effective transition of care requires significant resources and calls for a multi-disciplinary approach involving the treating physician, the patient, their caregivers and family members, and the healthcare system, through the funding of positions for specialist transition nurses or coordinators [48].

Spotlight on the US



A survey of 67 EoE patients in the US highlighted meal planning, food shopping, cooking/finding foods that did not exacerbate their condition, and knowledge of insurance coverage as aspects that they struggled with most.

Although most respondents reported confidence in having the knowledge to manage their EoE, almost half of the respondents worried about managing their condition in the future. Resources detailing diet, medication and insurance management strategies could support the transition to adult healthcare for patients with EoE. [49]

Evidence shows that **the transition out of pediatric care and into adult healthcare is often mismanaged**, stemming from gaps in knowledge, disjointed communication and an absence of standardized protocol [12].



"For effective transfer of medical care, facilitating multidisciplinary collaboration among allergists, gastroenterologists, paediatricians, dieticians, psychologists, and social workers has also been recommended to improve continuity of care through a shared decision-making process." [12]

Best practice examples from Spain

Transitioning from pediatric to adult care

To support patients at this crucial time, Spain has been introducing so-called 'Transition Units', starting with several hospitals located in larger cities such as the Niño Jesús Hospital and the Puerta de Hierro Hospital in Madrid and the Vall d'Hebron Hospital in Barcelona.

Implementing multi-disciplinary care approaches

The EoERed project is a collaboration between the La Princesa University Hospital in Madrid and AEDESEO (with the support of Sanofi), which aims to increase access for patients to specialties such as nutrition, psychology, speech therapy, and social workers, beyond the clinical care they receive [51].

Training for teaching and non-teaching staff in public schools

With the objective of ensuring children living with EoE are not further isolated in school, AEDESEO has launched a training program, which is currently being piloted in the Murcia Region and in the Valencia Community [52].



Lifelong disease self-management remains difficult to achieve

EoE is a chronic, progressive condition which requires lifelong management of inflammation, with a combination of medical and non-medical approaches that require willingness and motivation to ensure adherence. **Patients face challenges ranging from adherence to treatment, mental resilience, access to expert resources, for instance specially trained dieticians or mental health professionals who are familiar with EoE and its burdens, to the actual cost of specialist food or accessing therapy.**

Current medical guidelines [24] recommend dietary therapy, **pharmacological therapy** – proton-pump inhibitors (PPI), topical glucocorticoids (TCG), biologics – and **endoscopic therapy**.

Clinicians routinely refer to a combination of approaches as each have their limitations as long-term therapies for EoE. Common challenges around pharmacological therapy – **PPI and TCS** – include partial efficacy, unproven long-term efficacy [53], high occurrences of relapse [54], and lack of long-term safety data [55].

Advanced **biologic therapies** are recommended for patients with EoE and there is proven evidence of the mechanism of action across T2i diseases, increasing their impact for comorbid patients [56]. However, despite the inclusion of advanced and biological therapies in medical guidelines, these therapies are generally only considered after the failure of first-line treatments, limiting the benefit they can have for patients [24].

Maintenance therapy is generally necessary for at least one year [23] because the disease frequently recurs after discontinuation of treatment, and ongoing suppression of inflammation is crucial to prevent fibrosis and esophageal remodeling. However, it remains an understudied area with questions around how to define sustained remission, what the best maintenance strategies look like and how to enhance treatment adherence and long-term disease monitoring [57].

> “The most commonly recommended dietary therapy eliminates the six common allergenic foods commonly linked to food allergy in EoE.
>
> These foods are ranked based on their allergenicity as follows: cow’s milk, wheat, egg, soy, peanuts/tree nuts, and fish. As expected, this six-food elimination is more effective than gradual food elimination, where one or two foods are eliminated for up to 12 weeks, followed by endoscopy. However, six-food elimination is very challenging, especially for children, where compliance becomes an issue.” [15]

Management of EoE is therefore lifelong, requiring a patient to manage a combination of approaches to maintain control and reduce relapses. **There is currently little in the way of a cohesive, personalized multi-disciplinary care approach** that takes a holistic view of coexisting diseases and encompasses mental health aspects of managing the disease. Equally, a **lack of consistent shared decision-making approaches** is also seen as an additional barrier to a patient achieving consistent disease management [58].



"Patients will benefit from being cared for by a multidisciplinary team, which should include the treating physician or the gastroenterologist, allergist, psychologist, general pediatrician, and dietitian to support patient care, avoid any conflicts regarding the advice given, and reduce the number of clinic visits." [59]

How does EoE affect quality of life?

Patients must significantly adapt their lifestyle and how they approach routine interactions

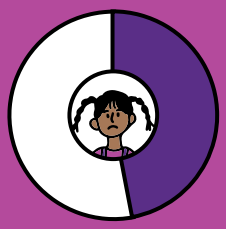
Distinctly, being diagnosed with EoE means some patients must **incorporate changes to their diet and change the way they eat and interact with food, while already managing cumbersome adaptive behaviors and resulting conditions such as phagophobia** (fear of swallowing [38]). This will change how they view and prepare for social interactions and create anxiety [60]. It may also lead patients to withdraw from social situations due to the omnipresent risk of relapses when approaches are adjusted [60].

Restrictive diets greatly impact health-related quality of life in patients with EoE and place additional strain on their relationships with family and friends, especially when there is a need to ensure availability of tolerated foods at family gatherings or at social or community gatherings [10].

From a patient's perspective

EoE patients frequently report anxiety over food and portions, including how to eat enough to maintain a healthy weight and how to avoid choking [6].

Beyond the social impact, EoE significantly affects an adult's ability to work, with consequences spanning emotional, practical, and economic domains. **The disease has a significant impact on sleep and vitality, and its management requires a person to take regular time off from work** [41]. A study of adult patients in **Italy** estimated that a total of 4.6 days per month were lost to disease management [61].



Up to 43%

of children with EoE experience anxiety and/or depression.

EoE has a negative impact not only on physical health, but also on mental health, with percentages of anxiety and depression ranging from 15% to 43% [of children], and which may require referral to mental health in up to 47.2% [of cases]. [62]

Spotlight on Germany

The DGVS guidelines on EoE come to a strong consensus that health-related quality of life (HRQoL) is relevantly reduced in children and adults with active EoE, with psychological and social consequences. This is due to the chronic course, limited therapeutic options and need for close clinical and endoscopic-histological follow-up [6].



Bolus and choking anxiety as well as the general burden of the disease determine HRQoL.



Symptom severity correlates strongly with HRQoL.



Available treatment options significantly improve HRQoL, while overly restrictive diets have the opposite effect.

The impact on quality of life is considered greater still in children as they learn to navigate the world, lay down the foundations of their social interactions and strive to do well in school. **Dietary restrictions and symptom management may interfere with a child's ability to focus or participate in ordinary activities such as school meals.** Children may fall behind in their studies and build up further anxiety. This also significantly affects school performance by creating hurdles to participation in educational and social activities [59].

As a result, **over two-thirds of children with EoE report psychosocial difficulties, including issues integrating and interacting with peers (particularly in school), anxiety, depression and even sleep issues** [12]. This requires greater attention from teachers and educators and thus better training to ensure they can provide the necessary support to these children [63].

Considering all the above, it is no surprise that living with EoE triggers stress, anxiety and in some cases depression. **The incidence of depression and anxiety is reportedly higher in patients with EoE than in the general population** [41]. The general onset of anxiety disorders usually occurs in childhood/adolescence, until they reach a peak in middle age, with a tendency to decrease with older age. In a study of 147 adult patients, 24% demonstrated signs of an anxiety disorder and 10% suffered from depression. Moreover, it is estimated that there is a three-fold risk for high levels of anxiety in EoE patients between 18 and 35 years old [7].

Increased mental load on caregivers

Stepping beyond the more overt clinical burden on patients, EoE negatively impacts the **mental health of caregivers** as they strive to reorganize their lives to support the children they care for and help them manage the disease.

Managing dietary restrictions – monitoring intake, avoiding allergens, and preventing nutritional deficiencies – can be highly stressful, especially with the constant worry about adverse reactions or developmental delays [15]. These challenges are compounded by frequent medical appointments, which

may require time off work and long-distance travel [12].

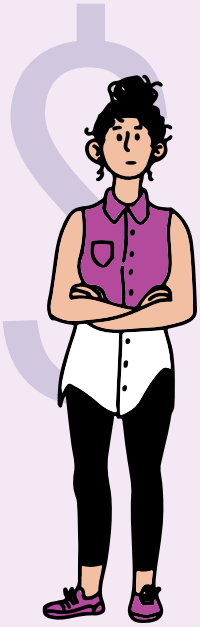
As a result, caregivers tend to withdraw themselves, and the children in their care, from social events, in some cases leading to feelings of isolation, increasing stress and anxiety [15] [60].

What are the costs associated with EoE?

The visible costs for healthcare systems

Healthcare systems continue to face the economic burden of managing EoE, which exceeds that of other conditions like inflammatory bowel disease (IBD) and celiac disease [15]. **The cost of managing EoE includes inpatient and outpatient care, frequent monitoring, increased likelihood of emergency department visits, repeated endoscopies** [12]. Moreover, the costs of therapies can be higher than those for other chronic inflammatory diseases and will be compounded in the case of comorbid patients [15].

Spotlight on Italy



Managing EoE incurs a significant burden on healthcare systems, amounting to €6,852.28 per patient per year.

The primary cost component appears to be **direct costs, comprising 60.73% of the total cost** per patient for this condition, while **indirect costs contribute to 29.68%** of the overall management expenses.

[61]



Typical **unseen costs** associated with managing EoE:

- Loss or change of work status
- Specialist food
- Private healthcare
- Medications
- Private tuition
- Travel and accommodation

[64]

The unseen costs on patients and caregivers

Often overlooked by HCPs and policy-makers, an important consequence of EoE is the **financial burden** it places on patients and their families, driven by costly treatments and lack of access to care or approved medications, leading to out-of-pocket payment for private healthcare and, in some cases, off-label medications.

Families with children suffering from EoE feel this strain acutely, as treatment can cost twice as much as for adults. This disparity is also reflected in broader economic pressures, where caregivers often find themselves reducing work hours or leaving their jobs entirely. The burden continues to be carried by adult patients following a strict elimination diet, with estimated additional costs of $650 to $720 annually to purchase specialty foods [10].



Families and caregivers of pediatric patients with EoE face increased financial burdens.

Pediatric cases carry an average annual cost of $4,001, which is significantly higher than the estimated $1,906 annual cost for adults [12].

Furthermore, caregivers of children and adolescents with EoE have estimated annual indirect costs of $2,473 and $16,487 due to reduced working hours and stopping work, respectively [12].



Despite the increasing prevalence of EoE, the **societal economic burden of the disease** remains largely unstudied. Existing data on the financial impact of EoE is predominantly limited to the United States, and no previous studies have thoroughly examined indirect costs, such as work loss [13].

Symptoms and treatments also have a direct impact on productivity, with doctors' appointments identified as the most frequent reason for absenteeism for patients in one study (50% of patients), while 35% of patients missed work or school-related trips because of the disease [9].

The **psychosocial stress of EoE and its management can affect the mental health and social functioning of patients and caregivers**, further contributing to the unseen burden on them as they need to cover the costs of therapy [10]. While referrals to psychologists for all EoE patients might not be possible, psychosocial stress should be assessed together with the disease and referrals to specialists should be offered to patients based on the results of screening for mental health conditions.



"As a mother of a 5-year-old suffering from EoE, I am experiencing first-hand the cost, time and mental burden associated with helping my daughter navigate a complex system with very limited access to care and specialists. In Spain, the role of the caregivers is very much overlooked because EOE is currently not recognized, therefore caregivers are not entitled to benefits such as working time allowance, care leave and the maintenance of pension contributions. Official institutional recognition in the Official State Gazette (BOE) would at least help me get financial support and claim for reduced working hours to spend more time with my daughter as we help her manage this debilitating condition."



EVA GARCIA
Vice President of AEDESEO, Spain

Methodology

At the start of the project, research was conducted by Weber Shandwick in the form of a rapid literature review with a focus on the global landscape, Europe (with a focus on four European countries: Germany, Italy, Spain, and the Netherlands) and the United States. The review included free-access scientific and academic articles published between January 2020 and January 2025, accessible through two platforms: PubMed and EMBASE.

It was complemented by desk research looking at data generated and other information published by relevant organizations (e.g. patient advocacy organizations) over the same period. This research aimed to collect information around a number of key questions across four pillars of research (see below):

Once the data was collected, the position paper was developed by Weber Shandwick in close collaboration with the three authors of this paper (representatives from EOS Network, APFED, and GAAPP) – the Steering Committee – with the support of Sanofi & Regeneron. This collaborative process included a total of four meetings in addition to offline work and review time. The wider group of patient advocacy group representatives and individual patient advocates that ultimately endorsed the paper and its policy recommendations – the Advocacy Board – was also invited to attend one of these meetings virtually. This group ultimately reviewed, validated, and endorsed the paper. Both the Steering Group and the Advocacy Board were convened by Sanofi & Regeneron.

1. Disease manifestations and mechanisms

- Sub-types / sub-populations / phenotypes
- Grades of severity
- Etiology
- Risk factors
- Incidence
- Prevalence (information on under-diagnosed population)
- Prognosis

2. Burden of illness

- Co-morbidities
- Mental, emotional and social wellbeing
- Ability to go to school/work and stay active
- Direct costs
- Indirect costs

3. Unmet needs

- Diagnosis challenges
- Challenges in medical management and care
- Treatment challenges (non-biologics)
- Treatment challenges (biologics)

4. Barriers in access to medicines

- Barriers in access to biologics
- Barriers in access to non-biologics

Disclaimers

This position paper represents the views and opinions of its authors only, who bear sole responsibility for its content. This document aims to provide a comprehensive overview of the current landscape of EoE management in Europe and globally, but it is important to note that it does not constitute an exhaustive or scientific review.

Instead, the rapid literature review, conducted by Weber Shandwick, offers valuable insights into various issues affecting a diverse cross-section of EoE patients. The information collected was reviewed by authors of the position paper, ensuring that the most relevant and up-to-date data was incorporated into the final document. The position paper was developed with the unrestricted support of Sanofi & Regeneron, reflecting the necessity of collaboration between the EoE patient advocacy community and the pharmaceutical industry in addressing the gaps in the care pathway for EoE patients.

All photos are for illustrative purposes only and do not depict real patients or medical professionals.

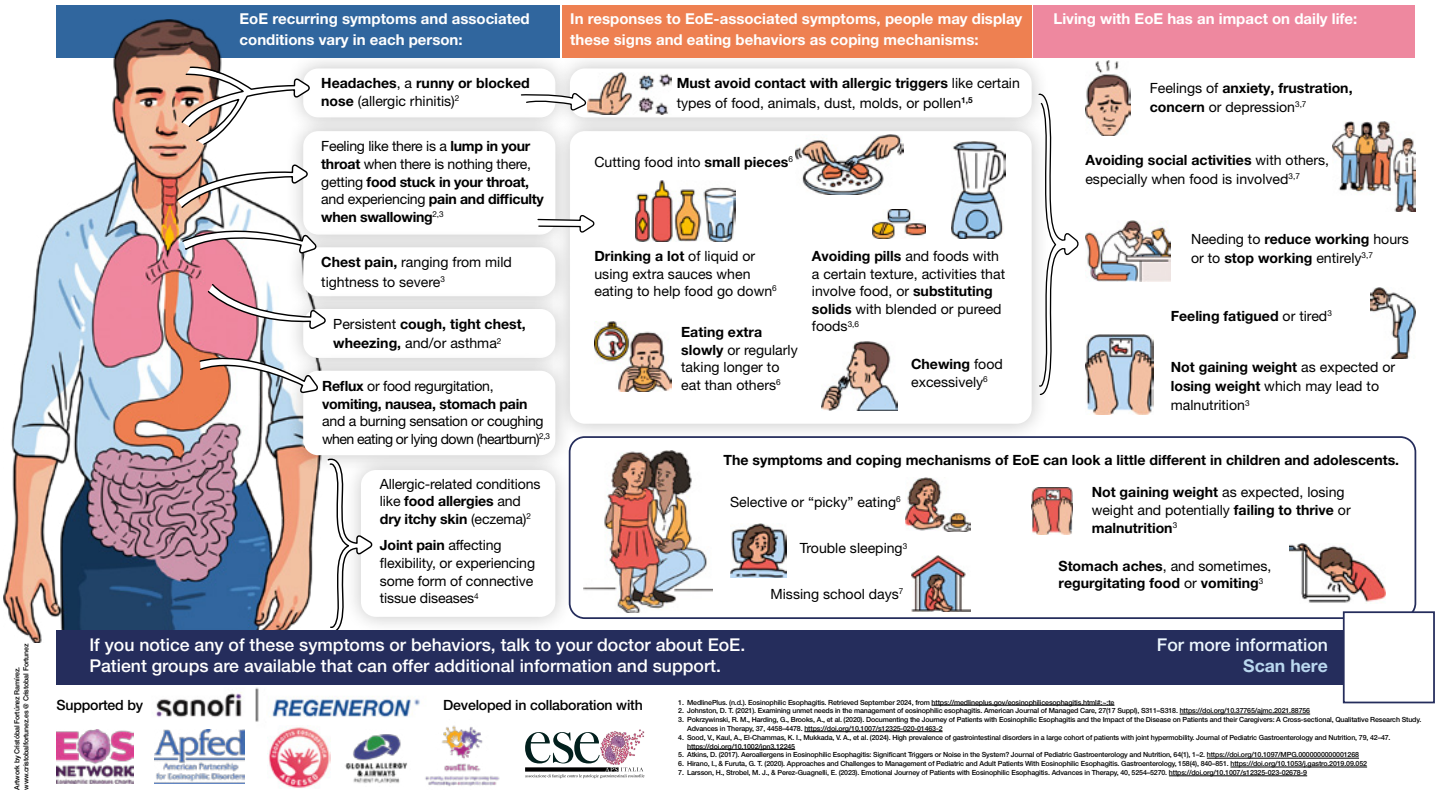


Infographic

In 2024, the EoE community came together to co-create an asset to help explain EoE signs and symptoms as well as the adaptive behaviors that could evolve in response to these symptoms. This educational asset has been used to engage people living with EoE and their caregivers, as well as patient advocates.

COULD IT BE EOE? THE SIGNS AND SYMPTOMS

Eosinophilic esophagitis (EoE) is a chronic and progressive disease that can occur at any age.[1] EoE is caused by an underlying inflammation, which can damage the esophagus (the tube that takes food from your mouth to your stomach). Often linked with a personal or family history of allergy-related conditions, its symptoms vary widely and can affect the entire body. People can experience one, some, or all EoE symptoms, which may vary depending on age. As EoE is a silent condition, understanding behaviors that help people with EoE cope with symptoms (both consciously and unconsciously) is important. This guide will help you better understand the possible associated symptoms of EoE and common coping mechanisms to look out for.



Artwork by Cristobal Fortunay Ramirez. www.cristobalfortunaza.it/ © Cristobal Fortunay

Supported by sanofi | REGENERON Developed in collaboration with

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More educational, awareness, and advocacy resources are available on the World Eosinophilic Esophagitis Day website.

eoeday.org

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