



Mapping Breathlessness Together: ERS 2026 Perspectives on Patient-Centred Symptom Care

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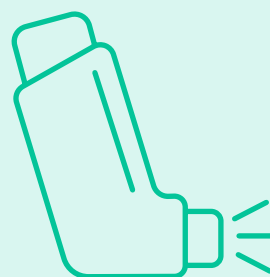
NO SINGLE MAP OF BREATHLESSNESS

Breathlessness is often approached as a physiological concern: clinicians identify its underlying cause, measure respiratory impairment, and select an appropriate treatment. Yet physiological findings alone may provide only a partial map of the patient's experience. How breathlessness is perceived, interpreted, described, and managed is also shaped by emotions, expectations, language, culture, and social context. Across scientific sessions, poster presentations, and discussions with patient representatives, the European Respiratory Society (ERS) Congress 2026 highlighted the importance of bringing these dimensions together.

MAPPING A MULTIDIMENSIONAL EXPERIENCE

Breathlessness involves physiological processes, but it is ultimately experienced by a person. This distinction was reflected across several ERS 2026 contributions. In the experimental study by Volpato et al.,¹ menthol inhalation reduced the perceived intensity and, more modestly, unpleasantness of induced breathlessness without detectable changes in ventilation, illustrating that symptom relief can occur at the perceptual level. Complementing this

finding, Hayden et al.² found that, among 412 people with uncontrolled asthma, the Nijmegen Questionnaire was strongly associated with anxiety and depression but not with forced expiratory volume in 1 second, suggesting that it captured a multidimensional symptom burden rather than clearly separable breathing domains. Together, these findings underline why breathlessness cannot be fully represented by either physiological parameters or a single questionnaire.



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This complexity extends beyond symptom measurement. The systematic review by Hutchinson et al.³ of 101 qualitative studies described the widespread effects of chronic

breathlessness on patients and carers, and introduced the concept of 'breathing space'. The space available for living was shaped not only by disease, but also by the patients' coping and help-seeking behaviours, as well as clinicians' responsiveness to breathlessness. Thus, understanding the symptom requires attention to not only what patients feel, but also how they interpret, communicate, and manage that experience and how HCPs respond.

FINDING WORDS AND SHARING A MEANING

Understanding breathlessness also requires language capable of conveying what changes when breathing becomes pathological. At the ERS Congress 2026, Havi Carel, Department of Philosophy, University of Bristol, UK, distinguished between ordinary breathlessness, which is usually transient, familiar, and contained within everyday life, and pathological breathlessness, which crosses those boundaries. The latter can undermine a person's sense of bodily safety, introduce unpredictability, and impose new limitations and rigidities on daily life.⁴ Yet these aspects of the experience may remain difficult to articulate during clinical encounters. Slavica Kochovska, Palliative Care, Flinders University, Adelaide, Australia, highlighted that patients' expectations about whether and how their breathlessness can be managed often have little place in conversations with HCPs.⁵ Stewart-Knight's qualitative study⁶ of asthma clinicians similarly identified a misalignment between patient and clinician beliefs, but showed how communication and trust could bridge it. Clinicians emphasised validating patients' emotions and experiences, recognising non-asthma conditions as real, and using biomarkers to establish common ground. These themes suggest that shared decision-making begins by sharing expertise and influence. What does the patient believe is happening? What do they expect can change? And what would living better with breathlessness mean to them?

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THE SOCIAL, CULTURAL, AND ENVIRONMENTAL LANDSCAPE

Breathlessness is experienced not only within the body, but also through a person's relationships with others and with the surrounding world. Alqarni et al.⁷ found loneliness to be considerably more common than objective social isolation among people with COPD. Loneliness was associated with greater breathlessness and symptom burden, poorer quality of life, anxiety, depression, and more frequent hospital admissions. Social contact alone may therefore reveal little about whether a person feels understood, supported, or able to share the experience of breathlessness. Drawing on ethnographic fieldwork in Uruguay, Megan Wainwright,⁸ Department of Anthropology, Durham University, UK, showed that breathlessness in COPD is shaped by culturally shared understandings of air, breath, and health. Participants related their breathing to humidity, temperature, wind, and perceived contamination. Describing breath as the mechanism and air as the medium of 'environmental embodiment', Wainwright proposed that bodies transformed by COPD become hyperperceptive and hypersensitive to changes in air. Breathlessness thus reflects an embodied, culturally interpreted relationship between body and environment, rather than an exclusively internal sensation or physiological response to exposure. These culturally situated experiences have practical implications for care. The co-design of a psychological intervention integrated into pulmonary rehabilitation in rural India by Singh et al.⁹ showed how community engagement informed adaptations to language, format, task sharing, and referral pathways. Culture is, therefore, not an additional characteristic to be recorded after assessment; it shapes how distress is understood and expressed,



which forms of support are acceptable, and how care can realistically be delivered.

DRAWING THE ROUTE TOGETHER

Recognising the multiple dimensions of breathlessness is meaningful only if it changes how care is developed with patients. Discussions during the European Lung Foundation (ELF) Patient Organisation Networking Day repeatedly returned to the importance of being heard throughout the patient journey, from the search for a diagnosis and recognition of symptoms to the development of trust and a therapeutic alliance. Patient-centred care therefore requires more than inviting patients to choose between predetermined options: their experiences must help define both the problem and the possible route forward.

That route cannot be assumed to be the same for everyone. In a survey of 12,272 people with COPD across five European countries, Farver-Vestergaard et al.¹⁰ found that perceived stigma increased with disease severity and was more prominent among women, younger people, and those living alone, with substantial differences between countries. These findings suggest that personal and contextual vulnerabilities may shape how safely patients disclose difficulties and engage with care.

Moreover, the route is rarely linear. Lundell et al.¹¹ described sustained physical activity in COPD as a gradual process involving safety and practical support, the acquisition of strategies, and increasing independence. Exacerbations could return people to an earlier phase, requiring renewed support rather than being interpreted as failure. Their core theme, 'reclaiming my old life: from surviving to living', captures the broader goal of breathlessness care. Clinicians and patients must continually redraw the route together, selecting strategies that remain meaningful, feasible, and responsive to changing circumstances.

CONCLUSION

Creating a map that places breathlessness within a broader context of perception, psychology, language, society, and culture requires scientific evidence, as well as conversation, trust, and recognition of patients' expertise. Only then can patients and professionals work together to identify a way forward that moves beyond merely surviving breathlessness to living meaningfully with it.

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