

## Impact case study (REF3)

<b>Institution:</b> University of Bristol		
<b>Unit of Assessment:</b> 30) Philosophy		
<b>Title of case study:</b> Not just a symptom: improving the understanding of breathlessness as a debilitating experience		
<b>Period when the underpinning research was undertaken:</b> 2007-2020		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Havi Carel	Professor of Philosophy	1/2/2013-present
<b>Period when the claimed impact occurred:</b> 2014-31 December 2020		
<b>Is this case study continued from a case study submitted in 2014?</b> N		

### 1. Summary of the impact

Professor Carel's Wellcome-funded *Life of Breath* research project has changed approaches to breath and breathlessness, transforming understandings, offering new possibilities for management and therapy, and reducing stigma. The project challenged and extended biomedical perceptions of breathlessness by articulating the role of cultural context and individual emotions in it. The project worked with breathless persons, patient support groups, carers, clinicians, and artists to explore the nature of breath and breathlessness, understand their complex cultural constructions, and develop the therapeutic potential of this work. The impact includes:

1. **Broadening health professionals' understanding** of breathlessness and changes to clinical practice;
2. **Improving patient experience** for breathless patients and disabled people;
3. **Influencing museums' and arts practice's** representations of breathlessness;
4. **Increasing public awareness** and reducing the invisibility of breathlessness.

### 2. Underpinning research

The underpinning research and impact have been generated via a Wellcome Trust Senior Investigator Award held by Prof Carel and Prof Macnaughton (Durham University) between October 2014 and March 2020. The project explored breathlessness from a health humanities perspective through interdisciplinary collaboration. It took a critically engaged approach to breathlessness, seeking to interact with those affected to reveal these invisible lives. The project aimed to develop a uniquely *philosophical* account of the experience of illness and to apply that account to breathlessness.

Carel's 2016 OUP monograph, *Phenomenology of Illness*, develops this account [3.1], supplemented by the third, expanded edition of *Illness* [3.2]. *Phenomenology of Illness* uses phenomenological principles to articulate the general structure of the distinctly pathological experience of illness. Carel's research reveals that this is characterised by loss, bodily doubt, bodily occlusion, and fundamental changes to social and spatio-temporal experience [3.1, 3.6]. This is contrasted with healthy bodily experience, in which the body is lived as transparent and taken-for-granted.

From 2014 onwards Carel applied this philosophical framework to a particular experience, prevalent in a range of diseases as well as at the end of life: breathlessness. Three fundamental ideas drive this work: first, that **breathlessness is highly subjective**, difficult to capture and quantify, and discords with objective lung function measurements. There is a pressing need to understand this experience because objective measurements do not reflect the subjective distress and debilitation it causes. Carel suggests that this lacuna can be addressed through phenomenology [3.1-3.3]. Subjective experience can be articulated via a 'patient toolkit' developed by Carel [3.1].

The second idea is that **pathological bodily experience is profoundly different to normal experience**. Whilst normal breathlessness feels safe, unchallenging, familiar, and even enjoyable, pathological breathlessness feels threatening, challenging, frightening and unpleasant [3.1, 3.3, 3.5].

The third idea is that **breathlessness should not be narrowly conceived as a medical symptom**, but viewed holistically as an experience informed by beliefs, expectations, emotion,

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and interoceptive input. The Bayesian brain hypothesis has been usefully employed by 'Breathe Oxford', demonstrating the profound effect of 'priors' on perceptions of breathlessness. Complementing this scientific work, Carel's work uses a philosophical and medical humanities approach to argue that breathlessness is not just a medical symptom [3.1-3.6].

Carel was awarded the AHRC Health Humanities Medal 2018: Inspiration Award and was shortlisted for the AHRC Health Humanities Medal 2018: Best Research.

### 3. References to the research

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- 3.1 **Carel H** (2016), *Phenomenology of Illness*, Oxford: Oxford University Press [Available on request]; reviewed 9 times, including in *The Lancet*; cited 213 times
- 3.2 **Carel H** (2018, first edition 2008), *Illness: The Cry of the Flesh*, London: Routledge [Available on request]; reviewed 7 times, including in *Philosophical Quarterly*, with 526 citations
- 3.3 **Carel H** (2018). Breathlessness: the rift between objective measurement and subjective experience, *The Lancet Respiratory Medicine*, **6(5)**, pp.332-333  
[https://doi.org/10.1016/S2213-2600\(18\)30106-1](https://doi.org/10.1016/S2213-2600(18)30106-1)
- 3.4 Williams T and **Carel H** (2017). Breathlessness: from bodily symptom to existential experience, in Aho K (ed.) *Existential Medicine*, Rowman & Littlefield, pp.145-159 [Available on request]
- 3.5 **Carel H**, Macnaughton J and Dodd J (2015). Invisible suffering: breathlessness in and beyond the clinic, *The Lancet Respiratory Medicine*, **3(4)**, pp.278-9  
[https://doi.org/10.1016/S2213-2600\(15\)00115-0](https://doi.org/10.1016/S2213-2600(15)00115-0)
- 3.6 **Carel H** (2013). Bodily doubt, *Journal of Consciousness Studies*, **20(7-8)**, pp.178-197  
<https://philpapers.org/rec/CARBD>

#### Grants

**Carel H** (PI) and Macnaughton J (PI), *Life of breath: breathing in cultural, clinical and lived experience*, Wellcome Trust Senior Investigator Award, October 2014 - March 2020, GBP1.5 million [www.lifeofbreath.org](http://www.lifeofbreath.org)

### 4. Details of the impact

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Carel's research [3.1-3.6] and Life of Breath (LoB) project have changed understanding of breathlessness amongst patients and health professionals, leading to new approaches and management of breathlessness. This work has **initiated a shift** from medical, patient, and lay understanding of breathlessness as a medical symptom to viewing it as a complex experience; **improved the understanding** of breathing at the limits (e.g. in end of life); **reduced the invisibility** of respiratory patients by representing their experiences; and **developed new ways** to address chronic and end of life breathlessness through holistic and mindfulness-based interventions. The main beneficiaries include health professionals, patients, arts and health practitioners, and the general public.

#### 1. Broadening health professionals' understanding of breathlessness and changes to clinical practice

This includes a. beliefs about breathlessness being a simple medical symptom and b. beliefs about the lack of effective treatment for refractory and end of life breathlessness. Since 2014, Carel has published recommendations aimed at healthcare professionals, include a policy report [5.1] which provided research-based recommendations for improved end of life care focusing on breathlessness, a move to holistic understanding of breathlessness, and the creation of dedicated breathlessness services. Carel also spoke to health professionals at numerous events, including a respiratory training day in Bristol (June 2019), plenary at the International Regulators Meeting (Glasgow, March 2019), respiratory training day (London, October 2019) and a keynote at the Royal College of Physicians of Edinburgh Symposium (March 2020). She was also invited to speak at the prestigious *Medicine Unboxed* (November 2018).

Through this engagement Carel's research has led to an increased and improved understanding of breathlessness amongst health professionals. A respiratory consultant at Southmead Hospital says: 'LoB has exposed me as a frontline respiratory consultant to a completely different way of understanding, communicating, and thinking about breathlessness. I feel able to make patient experience the defining focus of my consultations [...] LoB also informs the way that I teach

medical students and other healthcare professionals' [5.2]. The Director of Breathe Oxford, University of Oxford, says: 'I have found [Carel's] work [...] particularly impactful [...] This new thinking [...] will help facilitate development of individualised treatments for breathlessness' [5.2]. 'I think that it's definitely helped make me a more empathetic doctor and see things from the patient's perspective' [5.10]. A consultant oncologist and curator of *Medicine Unboxed*, says: '[Carel's] voice for the public and conditions around illness [...] has huge force' [5.2]. A respiratory occupational therapist says LoB research has changed her practice: 'I guess I don't think as much about the fear that people have the anxiety and fear behind it, I think about how it impacts their function, and how I can improve that and give them techniques and tell them to pace but I think it's the fear element that they talked a lot about that's really relevant that I'll take back' [5.10]. Another health professional says that Carel's ideas will make her 'more patient and more empathetic towards [her] patients with COPD' [5.10].

The LoB project's flagship exhibition, *Catch Your Breath* (April-September 2019, see below), was displayed at the Royal College of Physicians, with associated events attracting overall nearly 2,000 visitors, most of whom were physicians attending professional conference and meetings at the venue. 86% of visitors to an exhibition event rated the exhibition as 'very good' or 'excellent'. 76% said that the exhibition changed their understanding of breathlessness [5.4]. Carel's research has had international impact. The international Enactlab, based in Denmark, uses Carel's work in developing person-centred healthcare practice for nurses. Enactlab, in collaboration with the University of Oxford, delivered a workshop inspired by Carel's work to more than 400 nurses in Iceland, the UK, Denmark, and the US. The Director writes: 'we have worked on translating the conceptual foundation into better and more meaningful nursing practice [...] Carel's work [has] had a large impact on my work, and still has a large impact on healthcare professionals and people living with disability and illness' [5.2].

Carel's work has been taught internationally in medical schools and medical humanities courses, influencing future generations of physicians at the universities of Girona, Belfast, Berlin, Copenhagen, Washington, London, Lyon, Texas (Baylor and Austin), Victoria University Wellington, NZ, Durham, Lancaster, and Bristol. Her book *Illness*, now in its 3<sup>rd</sup> edition (2018), has influenced medical students and health professionals globally. A lecturer at the École Normale Supérieure in Lyon writes: 'The students really loved [*Illness*]; there was a very enthusiastic response and it really engaged them' [5.2]. A lecturer in Medical Humanities at the University of Girona describes Carel's guest lecture as 'a once in a lifetime opportunity for [the students]' [5.2]. LoB inspired a new MA course at the Freie Universität Berlin, 'The Politics of Urban Breathing'. The course designer writes: 'Designing this course was much inspired by the various works done by the "Life of Breath" project team' [5.2]. LoB researcher Kate Binnie has been invited to teach therapeutic breathing techniques to the Cambridge Breathlessness Service, which supports respiratory patients [5.2].

## 2. Improving patient experience: breathless patients and disabled people

LoB's phenomenological research uncovered the centrality of the lived experience of breathlessness, articulated novel aspects of patient experience, and revealed the salience of key points in illness, such as diagnosis, symptom exacerbation, and end of life. The project has supported breathless patients across the UK with new interventions informed by phenomenology and its emphasis on patient experience, such as a dance programme for respiratory patients, 'Singing for Breathing' groups, and offering patient groups mindfulness practice. Writer-in-residence at Durham University, poet Christy Ducker, worked with breathlessness sufferers to produce a poetry collection. The evaluation found that this deep engagement helped people with breathlessness to feel heard, validated, and empowered [5.4, 5.5, 5.9]. Feedback from the *Singing for Breathing Bristol* group was extremely positive, with the group describing the sessions as 'tremendously valuable' [5.9]. One participant says: '[the group] has been extremely useful getting me to breathe through my diaphragm and not through my chest, and that has been the most useful thing I've got out of this, and I still get.' Another says: 'it's helping me sustain the breath, it's helping me build my confidence towards singing as well. And I think it's helping with panic attacks' [5.9].

In 2020, LoB work was used in an NHS guide, 'Managing breathlessness at home during the COVID-19 outbreak', pointing to LoB resources tailored to Covid-19-related breathlessness

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[5.8]. Carel and Macnaughton contributed a humanities perspective on Covid-19 to the International Science Council [5.7].

Carel's patient toolkit, adapted for breathlessness in LoB research, helps patients discern and articulate the experience of illness. It has been used to design patient workshops in the US and the UK, and is currently researched in France, Denmark, the Netherlands, and the UK [5.2, 5.5].

The toolkit is currently used by the SHAPER project at King's College London to support and improve patients' quality of life [5.6]. Carel's philosophical articulation of a phenomenological concept she dubbed 'bodily doubt' [3.6] was the theoretical foundation for patient 'social camps', benefitting more than 1,000 patients per year, based on a programme developed in Denmark by Dr Kristian Martiny. He writes: 'I have been highly inspired by Havi Carel's work, especially [...] her concept of 'bodily doubt'. This conceptual work I have applied at the Elsass Institute to develop concrete 'person centred' healthcare strategies for working with physical disability and for developing and implementing 'social camps'. The camps use the concept of 'bodily doubt' to facilitate psychologically challenging physical activities in a safe social environment to develop a stronger experience of bodily certainty' [5.2].

Carel's monograph, *Illness* [3.3], has generated continued powerful responses from patients and carers across the globe. A heart disease sufferer from Moscow writes: 'I found it incredibly illuminating and helpful. It helped me immensely to think through my new life as a chronically ill person' [5.2]. An Australian carer writes: 'a big thank you for a very insightful book' and a US counsellor says: 'your work has enriched my own thinking on a number of matters, including relationships between practitioners and patients/clients and approaches to meaning making in counselling work' [5.2]. The book garnered testimonies from dozens of patients, carers and family members affected by illness, stating that the book has helped them understand their situation.

### 3. Influencing museums and arts practice: representations of breathlessness

LoB engaged with dozens of arts and health practitioners, who then went on to engage the public, including school children, patient groups and hard to reach groups. Artist Jayne Wilton, who was commissioned to create covers for *Lancet Respiratory*, says: 'the work of [LoB] enabled me to extend my understanding and articulation of my practice' [5.2]. Director of Viv Gordon Theatre Company says: 'LoB has introduced me to a phenomenological approach to researching and writing theatrical material. Something I have been doing intuitively but now have a framework for – seeing it successfully translated onto stage and resonating with audiences gives me confidence to integrate this approach in other works' [5.2].

LoB researchers collaborated with the Thackray Medical Museum to include research relating to breathlessness and measurement of breath in their largest gallery. The Museum curator writes: '[LoB] work will contribute towards the redevelopment of the museum and the improvement of our public offer' [5.2]. Carel also influenced the curatorial framework used at the Mutter Museum, Philadelphia, where the curator stated that Carel's work influenced her approach and she found it gave her the confidence to use the controversial term 'failing bodies' in a wall panel [5.3].

Two medical poems on breath inspired by Carel's work have been published: 'She's breathing', by Alexandra Parvan (<https://lifeofbreath.org/2020/05/shes-breathing-a-poem-by-alexandra-parvan/>) and 'The unmapped geography of breath', by Dr Emily Wills, published in *Mortality* 25(3).

### 4. Public awareness and debate: reducing the invisibility of breathlessness

Public engagement was central to LoB, including stalls at science and nature festivals, workshops for children and adults, co-production of murals across Bristol, an art exhibition, a theatre show, *Book of Jo*, based on Carel's monograph *Illness* [3.3], public talks and panel discussions, poetry readings, community engagement (e.g. Fun Palaces programme), Feel It – a festival exploring breathlessness and pain, as well as active and creative online presence [5.4]. A Feel It festival audience member described the festival as 'cathartic [...] an epic experience' [5.10].

*Catch Your Breath*, the first exhibition ever to focus on breath, drew directly on LoB research to raise public awareness and challenge viewers to think differently about breath. The exhibition was hosted at Palace Green Library, Durham (Nov 2018–Mar 2019), the Royal College of Physicians, London (Apr–Sep 2019) and Bristol Southmead Hospital (Oct–Dec 2019) and Bristol

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Central Library (Jan-Feb 2020). A pop-up version toured UK libraries and medical conferences (Autumn 2019-present). It included literary and cultural artefacts and new commissions, tracing historical and cultural connections between breath, body, mind, and spiritual inspiration. The combined visitor numbers for the exhibition are c.10,000, with a further 21,000 visits to the exhibition website <https://catchyourbreath.org/>. Bristol's Southmead Hospital footfall is estimated at 21,000 and the Central Library at 40,000 during the exhibition [5.4]. The exhibition was featured on London Live TV and reviewed favourably in *The Lancet*, *The Lancet Respiratory* and *The British Medical Journal*. A two-page exhibition feature in the RCP members' magazine was circulated to 36,000 RCP fellows worldwide. The pop-up exhibition was shown in 5 libraries, reaching approximately 1,000 people [5.4]. The pop-up exhibition was invited to the WHO International Air Quality Summit (October 2019) and the Dyspnea20 medical conference (rescheduled to 2021). Comments about the exhibition included 'Breathlessness is not something to be ashamed of and should be discussed more openly', 'Better understanding of the scale of the problem and how the arts can improve public appreciation' [5.4].

LoB has invested much thought and planning into increasing its reach via an attractive and rich online presence. By November 2020, the website had over 190,854 views, with 166 posts; its most popular blog '*Singing for Breathing*' had over 4,185 views [5.4]. The blog won Healthline's 'Best COPD Blogs of 2019' award. LoB recorded 11 podcasts, with 2,959 listens. The most popular is 'Breath in Visual Art' with 1,015 listens. The project attracted 1,623 Twitter followers (10,000-20,000 tweet impressions per month) and 580 subscribers to its newsletter [5.4]. LoB hosted a Twitter Chat on the British Lung Foundation's report, *The Battle for Breath*. It has 263 Facebook followers, with a typical post reaching 109 followers. The project featured on the Wellcome Trust's Facebook as 'Team Heroes' (<https://www.facebook.com/notes/wellcome-trust/an-exploration-of-breathing-and-breathlessness/10156786798576918>). LoB featured in local and national media more than ten times, including an interview of Carel in a BBC film documentary, 'The disability paradox'.

2,500 adults and children visited the LoB stall at the Science Festival in Durham in 2017, and 3,000 visited a stall in Bristol's Festival of Nature in June 2018. Carel also presented work on breathlessness at FUTURES European night of research 2019 at *We the Curious* (September 2018), coupled with a project stall visited by 300 school children. Carel organised and chaired a panel on breath at the same event in 2020 (online, November 2020) [5.4]. An audience member said: 'It made me more aware of the effect of breath and breathing on feelings, physical and mental wellbeing both in myself and people around me and making me want to share this awareness and encourage others to be more breath "literate"' [5.2].

### 5. Sources to corroborate the impact

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- 5.1 Life of Breath policy report (November 2018)
- 5.2 Email testimonies from beneficiaries (2019-2020)
- 5.3 Interviews with beneficiaries (2019-2020)
- 5.4 Life of Breath digital communications summary (November 2020); Life of Breath activity report (December 2020); Writer in residence evaluation report (September 2019); *Catch Your Breath* evaluation report (July 2020)
- 5.5 [Narrative Dimensions Team](#) [Accessed 17 February 2021]
- 5.6 King's College London (KCL) project [UNS98807 Scaling-up Health-Arts Programmes: Implementation and Effectiveness Research \(SHAPER\)](#) [Accessed 19 February 2021]; KCL event (December 2020) [From feeling to knowing – putting imagination and lived experience at the heart of understanding illness](#) [Accessed 19 February 2021]
- 5.7 Carel H and Macnaughton J (April 2020), [Life of Breath – The perspective of the humanities on COVID-19](#), International Science Council [Accessed 19 February 2021]
- 5.8 Higginson IJ *et al.* (April 2020) on behalf of the NIHR Applied Research Collaborative Palliative and End of Life Care Theme, [Managing your breathlessness at home during the corona virus \(COVID-19\) outbreak](#) [Accessed 19 February 2021]
- 5.9 Feedback from Singing for Breathing Bristol group (October 2018)
- 5.10 Interviews conducted at project closing celebration (March 2020); [Feel It festival video interviews](#) (December 2016)