

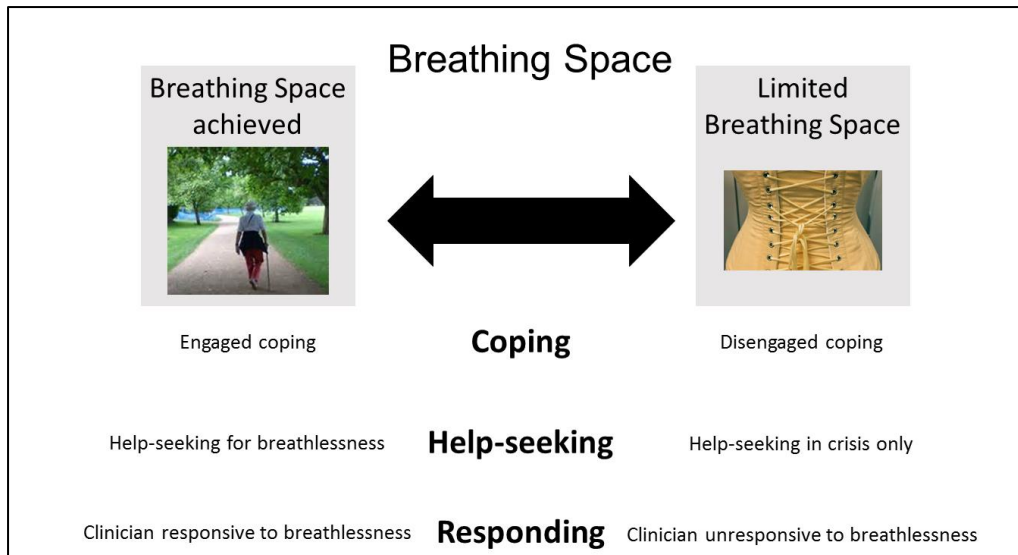
How can clinicians help people to live well with breathlessness?

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Millions of people around the world live with breathlessness due to underlying cardiorespiratory conditions. Living with breathlessness can be very difficult both for patients and for those who care for them, as it raises physical, psychological, social and existential issues for all concerned. It causes difficulties moving around and doing everyday things, becoming dependent on others, feelings of depression or anxiety, changes in relationships and roles and fears about the future and dying.

Clinicians can help people manage their breathlessness better. From our systematic review of qualitative literature on the experience of living with breathlessness, we developed the concept of Breathing Space. This incorporates an old English phrase used since the 1600s meaning “a period of rest that allows you to get your energy back or try a different solution” and “sufficient space in which to move and work” and a specific definition of quality of life, “The degree to which a person enjoys the important possibilities of his or her life.” We use Breathing Space as a concept to describe the experience of living with breathlessness: i) rest from the constraints imposed by breathlessness; ii) space and time to recoup strength and then plan further action and iii) the circumstances under which one can find one’s priorities and then fulfil them.

The Breathing Space concept helps us to understand how clinicians can work with patients and their family members and friends providing care to improve their lives whilst living with breathlessness. The figure below shows how the way a patient copes with and seeks help for their breathlessness, and whether and how their clinician responds to the *symptom of breathlessness* (as distinct from the causal medical condition) is important in how much Breathing Space can be achieved for the patient and those caring for them.



Restricted Breathing Space is characterised by avoidance, resignation and stagnation; summarised by the phrase “Life stops”:

“It just stops your life, stops you from living.” (Patient) (1)

“You fall into a huge hole, then the world gets so tiny, it all gets so narrow that it is almost unbearable.” “I feel like Sleeping Beauty. The hawthorn hedge has closed around me and I cannot do anything about it.” (Carer) (2)

A greater degree of Breathing Space is characterised by acceptance, adaptation and participation and can be summarised by the phrase “Life changes”:

“I’ve sort of changed my life. You can’t do the things you used to do, so you’ve got to say “well, okay, what can I do?” and do it.” (Patient) (3)

Despite the widespread effects of breathlessness on people’s lives it is possible to achieve a reasonable degree of Breathing Space by using engaged coping strategies (such as pacing, prioritising, accepting their situation, being active and keeping in touch with others) and by seeking help from clinicians who can guide them on how to manage their breathlessness.

“Walking was so difficult and we were supposed to bring our swimming gear and bottles (referring to oxygen tanks), so I got a wheelchair and the children pushed me and then parked me somewhere...I sat there and drank coffee and read...and occasionally they came over to touch base...it was great...but they could hardly reach the handles to steer and people didn’t get out of the way...so I had to call out beep beep (laughter)...it probably looked pretty funny...but we had an outing anyhow, and that was the main thing.” (Patient) (4)

Clinicians could support people living with breathlessness to achieve Breathing Space by assessing how breathlessness is affecting their lives, how they are coping with it and seeking help for it by using Breathing Space as a framework for a review and then tailoring breathlessness management strategies to match their needs using the [Breathing, Thinking, Functioning](#) model and the holistic approach to breathlessness developed by the [London Respiratory Network](#). By focussing on the symptom as a therapeutic target in its own right, clinicians can support patients to adopt more engaged coping approaches, more self-management techniques and help “move” them from “life stops” to “life changes”.

“She has got me organised and now I understand how the disease works. As a result I have had a good summer. It makes me feel more resilient.” (Patient) (5)

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