

The Breathlessness Clinic Westmead Hospital, Sydney

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General overview of service and the main components of the service: The Breathlessness Clinic is an innovative service for patients with chronic obstructive pulmonary disease (COPD) who remain breathless despite standard medical treatment.

Breathlessness is both distressing and frightening and up to 90% of patients with advanced COPD experience disabling breathlessness. The Breathlessness Clinic is a clinic designed to assist patients and their carers to control breathlessness so that it does not control them. The focus is on nonpharmacological measures which aim to allow patients to minimise the impact of breathlessness of their daily lives. While we may not be able to relieve breathlessness, we help patients find ways to 'outsmart' their breathlessness.

The clinic structure includes a screening home visit where baseline data is collected. Patients and their carers are then invited to attend an outpatient clinic where they are reviewed by a Respiratory Physician and a Clinical Nurse Consultant, both specialising in breathlessness.

The focus of the clinic is on the patient, what causes their breathlessness, what makes it better, what makes it worse, how does it make them feel and what they have tried in the past to control breathlessness.

During the clinic, the symptom of breathlessness is acknowledged and explained. The patient and carer are then given tips and tricks (non-pharmacological interventions) to help control their breathlessness based on the assessment findings. They are given a 'show bag' containing a DVD on breathlessness that reiterates concepts discussed in the clinic, to be shared with family members, a relaxation CD, various handouts about breathlessness and a hand held battery operated fan.

Hand held fans have been shown to decrease breathlessness and speed recovery. They are simple, cheap and portable but the science behind them, which includes a number of randomised controlled trials and several qualitative studies, needs to be explained so that patients understand that it is not a gimmick but a medically proven treatment for breathlessness.

After the clinic, the patient is discussed at a multidisciplinary meeting where allied health professionals discuss what other options may assist the patient and carer in dealing with breathlessness and a care plan is developed. Our allied health team includes a physiotherapist, occupational therapist, dietitian, psychologist and speech pathologist in addition to the Clinical Nurse Consultant and Respiratory Physician.

Interventions are then carried out in the patients' home during several home visits over a period of 8 weeks. The patient is then reassessed in the outpatient clinic. If the patient remains breathless, there is an option to be referred onto the clinical psychologist (if they have significant anxiety and / or depression), or for a trial opioid based pharmacological management.

Aims/objectives To assist patients and their carers to control breathlessness so that their breathlessness does not control them.

Patient demographic Patients with COPD (although in the future we hope to expand this to include all patients with chronic respiratory disease who remain breathless despite usual medical management).

Staff involved in delivering the service by discipline or health professional group.

- Respiratory Physician
- Clinical Nurse Consultant
- Occupational Therapist
- Physiotherapist
- Dietitian
- Clinical Psychologist
- We also have extra staff sitting in on clinic assessments as part of a training initiative.

Outcome measures include:

- Mastery of breathlessness (as measured by the Chronic Respiratory Questionnaire)
- Numerical rating scale of breathlessness at rest and on exertion
- Numerical rating scale of unpleasantness and confidence in managing breathlessness
- Hospital Anxiety and Depression Scale
- And a range of quality of life measures, and economic evaluation tools

Other comments / potential new initiatives

Dependent on the randomised controlled trial results of our study, we hope to roll the program out to other health services