

**Impact of the Breathlessness Research Programme  
on clinical practice and patient care:  
Cicely Saunders Institute, Kings College London**

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## **Executive Summary**

The Cicely Saunders Institute (CSI) has been conducting research into refractory/chronic breathlessness (breathlessness that continues despite optimal treatment of the underlying condition) since 2000. A major programme commencing in 2004 included establishing, as part of a Randomised Controlled Trial (RCT), an Integrated Breathlessness Support Service. Refractory breathlessness is a major issue for many people with advanced malignant and non-malignant diseases and results in high health social and informal care costs. Despite this, only Australia has medication (opioids such as morphine) licenced for its treatment and most treatments to mitigate symptoms are non-pharmaceutical therapies.

This report considers how the CSI research has impacted clinical practice and patient care and was compiled by interviewing, largely by phone, twenty-nine health professionals from twelve countries with an interest in breathlessness. The report finds that the CSI research has influenced research and, in some cases, policy in the breathlessness field as well as substantially increasing awareness and interest of the importance of breathlessness as a symptom and ways of mitigating its effects. Sixteen interviewees had set up Breathless Support Services (BSS) and the thirteen that had done so after the CSI RCT said the structure of their services has been strongly influenced by the CSI Integrated Breathlessness Support Services, though all had been adapted to meet the requirements and restrictions of their health systems. Key elements for a successful BSS include a multi-disciplinary team, secure finance, a strong relationship between the service, the patient and their families and an individual or individuals with a passion for improving services.

However, despite greatly increased interest in breathlessness as a symptom and the encouraging number of BSSs being set up globally, BSSs have not yet been replicated widely across any country's health services. Reasons for this vary between countries but include the difficulty of financing new services in an age of austerity, problems in recruiting staff with appropriate skills, the structure of some health systems, and, in some cases, resistance from respiratory physicians to a different approach.

The report concludes with some suggestions by interviewees of ways the CSI could further promote Integrated Breathlessness Support Services through continued research and collaboration, engagement with relevant professional societies and conferences and increasing the direct contact of interested individuals with the CSI through visits, fellowships and PhD students.

## **Introduction**

Breathlessness that continues despite optimal treatment of the underlying condition, often called refractory or chronic breathlessness, is common in many advanced non-malignant and malignant conditions. It has a devastating impact on people's lives, causing considerable disability and severely limiting their wellbeing and quality of life and that of those close to them. It is often a signal of deterioration in life-threatening non-communicable diseases and increases in prevalence towards the end of life. In addition, it results in high health, social and informal care costs and is one of the most frequent causes of emergency hospital admission and attendance.

Breathlessness affects over 75 million people worldwide every year, including:

- more than 90 per cent of the 65 million with severe lung disease;
- over 50 per cent of the 10 million with incurable cancer and
- 50 per cent of the 23 million with heart failure.

In the UK it affects over two million people a year. Yet, despite chronic/refractory breathlessness being a common symptom, apart from oxygen in cases of hypoxia, it is only in Australia that any medication is licenced for its treatment (opioids such as morphine). There are some non-pharmaceutical therapies that health professionals can use to mitigate the symptoms, but their use is patchy.

### **Scope of the report**

This report looks at how the Cicely Saunders Institute's (CSI) research has impacted views and practice in breathlessness management, how much the techniques, therapies and models of care to improve breathlessness have been taken up (or stopped if they are not effective) and their impact, with a particular focus on changes since August 2013. It also has some suggestions on how to promote and support further Integrated Breathlessness Support Services.

Twenty-nine people from twelve countries kindly agreed to be interviewed for this report. They included palliative care doctors, chest physicians and consultants, nurses (including specialist nurses) GPs, physiotherapists and commissioners of health services. A list of those interviewed and the countries where they work is at Appendix 1.

### **The role of the Cicely Saunders Institute (CS1)**

Refractory or chronic breathlessness is often described as a hidden and neglected symptom. Respondents gave several reasons for this. Partly it is due to the way medical care is delivered: Interventions tend to be disease based and patients can get lost in respiratory services that focus on a single disease and on treatment rather than ameliorating symptoms; care tends to be episodic rather than continuous and breathlessness is expected in many conditions. It is a complex symptom, which is not always the result of respiratory disease and requires a proper clinical diagnosis. It may also not become obvious until it is quite significant as patients often adapt their behaviour and activities to their level of breathlessness, or feel it is their fault, for example if the disease is due to smoking, and so not seek help early.

Since there are few medical treatments, doctors may see breathlessness as the patients' problem. David Currow, Adelaide, Australia has described this as 'therapeutic nihilism'. One respondent said a patient, a young man with COPD but also a range of other health problems, including rare conditions for which he was under national tertiary specialists, said that his conversation with this doctor (in a breathlessness support service) was the first time anyone had shown any interest in his breathlessness and how he could be helped to manage it.

The CSI has been conducting research into breathlessness since 2000 with a major programme commencing in 2004 that has the ultimate aim of developing new models of

care and treatment that are widely available. Within that programme the CSI, in partnership with Cambridge, created a multi-professional international collaboration of researchers and clinicians working in breathlessness from both palliative care and other specialities, including from brain imaging, respiratory disease and physiology. The collaboration was aimed specifically at improving research in order to improve care. John Moxham noted the importance in particular of the engagement between palliative care and respiratory medicine. This ensured that there was sufficient understanding of the physiological basis of breathlessness and that patients had a detailed explanation of why they were suffering from breathlessness. It was a factor in lessening the sensation of intensity of their breathlessness and feeling more in control.

Since 2000 CSI has published many articles and blogs on breathlessness and established, as part of a Randomised Controlled Trial (RCT), an Integrated Breathlessness Support Service (IBSS). This was an interdisciplinary service that provided two outpatient clinic visits to the CSI and a home assessment over a six-week period. Patients were seen by respiratory and palliative care physicians and their carer had access to a social worker. The patients were followed up by a home visit by an occupational therapist and a physiotherapist. Patients were also provided with a Breathlessness Support Service Toolkit with factsheets and resources to help them manage their breathlessness.

### **Research, raising awareness and impact on policy**

All of those interviewed knew of the research undertaken by the Cicely Saunders Institute (CSI) into breathlessness and those who had a continued interest in breathlessness said that it had, to a greater or lesser extent, impacted their practice, other research being undertaken and, in some cases, had influenced policy. The research most often referenced by interviewees was the October 2014 Lancet article on the Randomised Controlled Trial into 'an integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness'. Emma Grainger, Editor in Chief, Lancet Respiratory Medicine noted the importance of the RCT involving COPD patients as the focus previously had been on cancer patients. Information from the Lancet shows the 2014 article continues to receive a large number of views and since this data only refers to the Lancet.com there will have been many more view on other sites.

2016: 1,490 page views, 516 full text article views

2017: 1,614 page views, 956 full text article views

2018: 1,592 page views, 990 full text article views

2019: 625 page views, 625 full text article views

An associated Altmetric page, lists every place it appears around the net, including news sources, blogs, policy sources, tweets, Facebook posts, and other research platforms:

<https://www.altmetric.com/details/2819836?src=bookmarklet>

Also often mentioned by respondents was the Cochrane Systematic Review on non-pharmacological interventions for breathlessness

The research undertaken by the CSI has clearly been influential in other research and is often cited. Dr Deborah Dudgeon, Queens' University, Canada, said CSI's work had a profound impact on the field, producing many of the foundational research studies for

those working in breathlessness. Dr Charles Reilly, Kings College, London, UK, pointed out that, despite the increasingly competitive environment for research funding, there have been a number of large grants awarded based on the findings from the CSI's IBSS, including his own Clinical Lectureship, demonstrating continued interest and investment in this area of symptom-based research.

One key factor in spreading awareness, increasing research and changing practice in other countries is the direct influence of the CSI work on visiting research fellows and PhD students. These have gone back to their countries, Germany and Portugal for example, and continued to work on breathlessness.

There was general agreement that the CSI research had played a significant part in raising the importance of refractory breathlessness as a symptom and ways of mitigating its effects. Rob George, St Christopher's Hospice, London, UK, believed that the CSI had 'catalysed the whole movement of taking breathlessness seriously and looking at it systematically' and David Currow said CSI had taken an international lead on this subject. He highlighted as important Irene Higginson's (lead researcher and a clinical academic) background, grounded in the real world of health services, and the CSI focus on the patient and caregiver. Ewa Jassem, Gdansk, Poland, stressed the importance of CSI's qualitative research on communication and quality of life. Noel Baxter, London, UK as a commissioner of health services noted the helpfulness of the economic analysis in the 2104 Lancet article and Amy Dewar, London, UK agreed, having found the economic analyses in articles useful when advocating for resources for integrated breathlessness management services.

Most respondents said that they had experienced an increased interest in the topic of breathlessness. Several said that they were being asked more often to speak at conferences and that their presentations on breathlessness were meeting with increased interest. For example, Natasha Smallwood, Melbourne, Australia, had noted a significantly increased number of visitors to her clinic in the previous year. Noel Baxter, who is Chair of the Primary Care Respiratory Society, said breathlessness was often discussed and people within the society were enthusiastic about it. Claudia Bausewein, Munich, Germany, noted that she and to some extent her colleague in Cologne, Steffen Simon (both trained at the CSI in breathlessness), are seen by respiratory physicians as the 'breathlessness people', suggesting a raised profile but also that they were the only experts available on the subject.

There is evidence of impact on policy. CSI research has been referred to in numerous policy documents both in the UK and internationally. For example, the German National Guidelines on Palliative Care for People with Cancer mention breathlessness and cited CSI articles in the evidence. Dr Steffen Simon noted that this had impacted on strategy with hospital palliative care teams getting more resources. More widely, in the UK, Sara Booth, Cambridge, believes that the fact that the GOLD Standards Framework in the last two years have started to look at symptoms is a turning point.

#### **Impact on practice: breathlessness support services and use of techniques**

Sixteen of the interviewees were directly involved in setting up and running Breathlessness support Services and all but three (which had started earlier than the CSI trial) said the structure of the services had been heavily influenced by the CSI Integrated Breathlessness

Support Service (IBSS). Some had visited IBSS and its partner, the Breathlessness Intervention Service in Cambridge, for others a literature review had been the basis of their decision to build on the CSI model. However, all the services, even those most closely based on the CSI one, required some adaptation to the health systems and resources available in their countries. As Natasha Smallwood, Melbourne, put it 'each service develops as it goes along but ultimately you have to deal with the resources and structures that you have' while Kris Mooren, Haarlem, Netherlands, said that the health system should not be a barrier, but one should build on what already works.

An example of adaptation to a very different health system is the breathlessness support service in Singapore. Neo Han-Yee said that his service had been inspired and influenced by the CSI's research and the breathlessness services at Kings and Cambridge and took on board a number of ideas: e.g. individual crisis plans, a multi-disciplinary team, functional modifications and patient tools such as the hand-held fan. The service, however, is the only one in-patient based, with three weeks intensive rehabilitation. Although there is a specialist out-patient unit, the system does not allow for home-based visits and the engagement of families is more difficult culturally.

Though the breathless support services run by interviewees were generally based in clinics in hospitals, most had outreach into the community and patients' homes and all focused on non-pharmacological management of breathlessness. More generally, there is some evidence of the use and recommendation of non-pharmacological methods of assisting patients to manage their refractory breathlessness. For example, in the UK, the British Lung Foundation has patient information containing a number of the techniques and the Sydney service, which had as one of its messages 'be a fan of the fan' conducted a piece of research into the best hand-held fans and the 'winner' is now available through the Australian Lung Foundation.

### **What is needed for breathlessness support service to be successful?**

In all cases the setting up and development of the support services has been driven by one or more key individuals' passion for improving services for patients with refractory/chronic breathlessness. There needs to be funding: in several cases (Germany, CSI, ) the support service was originally set up as part of a research project, in others (Sydney for example), it was the result of finding a way to make the service fit with funding that became available from the local or regional health service. The INSPIRED programme in Canada, a home-based programme for patients with COPD, became the knowledge translation arm of earlier Federal and Provincial funding supporting the founders' research over several years into improving the Quality of Life for patients living with COPD.

Perhaps obviously, services need to respond to a real need and, once established, to create strong relationships between the patients, the family and the health team. In this context several of the interviewees mentioned the importance of home visits and a presence in the community as well as the Clinic or Hospice.

### ***The Breathlessness Support Team***

The team needs to be multi-disciplinary, though the exact conformation of this will vary from place to place and country to country. Miriam Johnson, Hull/York, UK notes that, in

the breathlessness support service set up at the Dove Hospice in 2000 and now at another Hospice and the Cancer Trust Hospital, a senior physiotherapist undertakes the initial assessment and works with the patient on non-pharma interventions, calling on other services as and when necessary. Alex Hough (UK) a physiotherapist, would agree this is a way forward. She is a strong advocate for there being much more access to respiratory physiotherapists for people with COPD and other diseases causing breathlessness. For example, she says that respiratory physios can halt the progression of bronchiectasis, although the formal position was that people die of the disease. She also believes there should be more respiratory Occupational Therapists and a breathlessness support service could be run by these two professions. Caroline Jolley (London, UK) noted the importance of psychologists who had experience of working with people with respiratory disease.

It might be assumed that Integrated Breathlessness Support Services would develop from established palliative care teams but, among the initiators of service interviewed for this report, there was only a very small majority of palliative care practitioners, with the rest being respiratory physicians, though mostly with palliative care specialist knowledge as well.

### ***Experiences of patients, families/carers and other professionals with breathlessness support services***

All interviewees were convinced of the value of their integrated breathlessness services and patient satisfaction with them. From a patient perspective, Mary Roberts, Sydney, spoke of the many grateful letters she received from clients who, together with their carers and families, felt able to manage their breathlessness and, to some extent, to lead an ordinary family life again. She also noted the positive effect on community nurses; it decreased their anxiety at being unable to do anything for their patients and increased their job satisfaction. Apart from the direct benefit of the non-pharmacological treatments, community nurses had also had a tendency to 'wrap patients in cotton wool' and encouraging them to use the techniques, including exercises, in the earlier stages of the disease could help delay the progress of symptoms.

Claudia Bausewein, Munich, had an astounding 90% response to a survey sent to patients four weeks after their six-week sessions, which suggests a high level of satisfaction with, and effectiveness of the intervention, with patients saying they used all the tools available to them. However, Claudia sounded a note of caution on assuming all techniques will be adopted. In a small embedded qualitative study as part of the wider RCT, people admitted they used the techniques sometimes or gave up (use of hand-held fans was one example). Claudia said it was essentially an individual response to the tools offered, she described it as offering a basket of goods with the patients choosing what worked best for them.

### **What are the barriers to establishing Integrated Breathlessness Support Services?**

There is no doubt that awareness of the symptom of refractory breathlessness has risen sharply over the period and that integrated breathlessness support services are emerging in a number of countries. However, with very few exceptions, the increased interest in integrated breathlessness support services noted by respondents has not yet led to these services being widely replicated across a country. Though many hospices in the UK, larger Hospices in the Republic of Ireland and hospice and palliative care services internationally run breathlessness support services they have not been widely adopted outside palliative

care. One exception is the INSPIRED programme in Canada, As well as the continued commitment of the founding team, Graeme Rucker, Halifax, Nova Scotia, noted the advantage of Canada having the Federally funded Foundation for Healthcare Improvement with whom, after the first two years, the programme was able to collaborate and roll out the programme first to 10 provinces and after to scale up further in 6 of them.

### ***Finance***

For all programmes finance is an issue, it is difficult to identify money for new services, even with potential long-term savings, in an age of austerity. In Pomerania, Poland, for example, there were originally five centres, but there was not enough funding to continue, so there is currently one centre based in the University Hospital, Gdansk. Several services have had to confine their help to patients with specific diseases, often COPD patients, because that was where the money was available. Tracy Smith, Sydney, noted that this raised concerns on inequitable access to treatment. Andrew Wilcock, Nottingham, UK, believes that part of the financial issue is a mismatch between evidence-based research outcomes and what boxes commissioners, in the UK at least, need to tick, which include cost savings and meeting specific targets. Graeme Rucker agrees, saying that independent economic analysis (every dollar invested offsets \$21) and other demonstrations of effectiveness and patient satisfaction are more effective in raising money from Health Departments than RCTs. Professor Nick Hart, London UK, pointed out the importance of integration between universities and hospitals: however good the research evidence is, the Trusts/Commissioners need to have ownership of it if a service is to be integrated into the health system and he also noted the importance of ensuring that the MDT tariff available for a service allows for there being a multi-disciplinary team.

Both Natasha Smallwood in Melbourne, Tracy Smith in Sydney and Claudia Bausewein in Munich have built up successful integrated services with permanent funding and Mary Roberts, Clinical Nurse Consultant with the Sydney service was very positive on the techniques moving further into the community.

### ***Health System Structures***

The structure of health systems can militate against the development of integrated breathlessness services. In systems with a fee for service model, there can be a perverse incentive to moving care from hospitals into the community, since this loses the acute services money. Natasha Smallwood highlighted the focus on specialists in Australia, who provide long-term support, and patients' reluctance to be discharged from their care. She cited the example of one patient who drove four hours, with an oxygen tank, to see their specialist, passing several hospitals on the way with respiratory physicians. Systems in some countries, for example Singapore, are explicitly centred on acute care and although the in-patient service has a link with a community hospital and patients can be referred to local hospices' day care programmes, the system does not allow for regular home visits. Massimo Costantini, Emilio Reggio, Italy, said that there were no integrated breathlessness support services in his country because it would be extremely difficult, in the Italian context, to create a multidisciplinary team around a patient's needs and also, because palliative care was not a speciality, the training was not rigorous enough to develop the skills necessary to work in the community. In the UK, because of the way the National Institute for Health and

Care Excellence (NICE) works, it can take five to seven years to get an evidenced intervention into its guidance.

Respondents generally felt that there was only patchy awareness and interest in IBSS among respiratory physicians. Several of those interviewed mentioned difficulties with collaborating with and obtaining referrals from respiratory physicians, even despite most of them being respiratory physicians themselves. This could relate to a fear that the services were 'taking patients away' and losing respiratory physicians money, inherent conservatism in relation to new models of care and, more generally, because there is a disease and medical, rather than symptom-based, approach to respiratory diseases and little or no understanding of non-pharmaceutical techniques. Anand Iyer, Alabama, USA, said that generally, his colleagues in pulmonology will use the established medical procedures. Rarely would a pulmonologist investigate or treat emotional symptoms or start an opioid and he had never seen a pulmonologist prescribe a non-pharmaceutical technique such as a fan.

The Irish Republic, however, has a national model for hospices in which consultant posts are shared between hospitals and the hospice. St Francis Hospice Dublin, as Karen Ryan reported, is linked with three hospitals two of which are national referral centres and the other the national heart and lung transplant centre. This means that the Hospice has relationships and partnerships with respiratory and cardiac physicians that are constantly developing, and they have some understanding of palliative care. Since pulmonary rehabilitation services are patchy in the Republic and currently only deal with patients well enough to get to the centres, respiratory physicians are happy to refer sicker patients to the Hospice, which has volunteer drivers.

While centres of excellence are important for training and demonstration purposes, the routine use of breathlessness management techniques in their clinics by individual clinicians is, Miriam Johnson points out, also important and is increasing. An example of this is the clinic at St Thomas' Hospital, London where Amy Dewar and her team focus on self-management for people with respiratory diseases and breathlessness and the COPD clinic has a psychologist, funded by a health charity. Having the techniques available within the clinic was also important since not all patients could easily reach the two Hospices whose breathless services it used, and others were too ill or geographically isolated to make it there themselves in the absence of hospital transport.

Having the right staff in place is crucial and, as Andrew Wilcock, Nottingham, UK, noted, it was not easy to move treatment into the community if the staff were not available. For example, he had found it difficult to recruit district nurses.

The complex nature of refractory breathlessness can also make it difficult to establish breathlessness support services within pressurised health systems. Several interviewees emphasised the importance of spending time with patients when they first present and listening to them. Claudia Bausewein acknowledged that in her service she was able to spend an hour with a patient when she saw them initially to do a rigorous assessment and most health professionals do not have this time. Sara Booth also emphasised the

importance of how the initial assessment is undertaken and of establishing a rapport, again stressing the time and skill elements.

Several people raised the issue of whether the labels of palliative care and hospices, and people's perceptions of them, were a barrier to integrated breathlessness services - and there was disagreement about this. Some interviewees felt people were grateful for help and support, whatever the label. However, Tracy Smith made the point that, as palliative care is often misunderstood as only for malignant disease and end of life, physicians don't refer and patients don't want to use palliative care or don't feel ready for it, so her clinic does not use the term. Amy Dewar also said that some of her patients would not go to hospices for breathlessness support.

On the other hand, as Tracy Smith also noted, in Australia, palliative care services were reluctant to take on people with non-malignant disease and who do not have a prognosis of death within six months. A third perspective is that from the Irish Republic. St Francis Hospice is increasingly being referred patients with earlier stage COPD, with staff having to take on patient management in a way palliative care does not normally do.

### **What did respondents suggest to further promote and support Integrated Breathlessness Support Services?**

Many of the issues preventing the establishment of IBSS are structural and cultural and will only change over several or many years. For example, Noel Baxter noted the importance of having the combined voices of cardiac, respiratory and palliative care services to effect change in services, but that this was not happening currently in the UK.

- Irem Patel believes that the UK's NHS 10-year plan offers an opportunity to instigate some change as respiratory disease is now a national priority, as well as an NHS Right Care priority and Sustainability and Transformation Plans (STPs) were being actively pushed to identify gaps and ways of doing things better.
- Another area where there could be more progress is in patient self-management. Many people with breathlessness do not get access to support and information. In response to the need for access to more self-help interventions, and building on the success of the IBSS at CSI and the Breathlessness Intervention Service at Cambridge, Charles Reilly, London, has NIHR funding to develop a self-guided internet-based intervention for people with breathlessness, aimed initially at those over 55 as they represent the majority of people going to A&E Departments with breathlessness. He believes that there is plenty of scope for promoting patients being more proactive in choosing interventions.
- Direct contact with the CSI's work through PhD and fellowship schemes, from visits and from the education workshops on breathlessness that Sara Booth had run at Cambridge had been very influential for some people and will be important in the future.

- Respondents were agreed on the importance of continued research and of collaboration. Caroline Jolley suggested that the CSI might do further research into the individual interventions within the Integrated Breathlessness Support Services to identify the ones which worked best and were most cost-effective. Miriam Johnson stressed the importance of using the same language and definitions to describe the symptom, although there are those unconvinced with the term 'chronic breathlessness syndrome' agreed on by the International Expert Consensus
- Opportunities to discuss breathlessness and raise awareness of the symptom at conferences were considered useful and several people noted the importance of engagement with the European Respiratory Society and its conference to increase the involvement of respiratory physicians although, as pointed out by an Australian interviewee, the cost of travel to European conferences meant that the ability to attend them was limited. Other societies and networks thought useful, included the Dyspnea Society and the Breathlessness Research Interest Group.

## **Appendix A.**

### **Contributors to the Report**

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