

# **What unpaid/family carers need to learn about supporting someone with breathlessness – and a web-based resource to support them**

NIHR ARC Palliative and End of Life Care  
National Leadership Webinar Series

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## Who are unpaid/family carers?

*“Lay people in a close supportive role who share the illness experience of the patient and who undertake vital care work and emotion management”*



# Supporting someone with breathlessness

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- **Considerable burden on carers**
  - multiple roles – overnight vigilance
  - restricting & isolating
- **Carers largely unsupported**
  - lack knowledge/ confidence/ strategies
  - helpless & powerless
  - anxiety → crises
- **Carer fear & anxiety** drives demand for emergency health care – *sometimes unwarranted & unhelpful*



## Carer support (breathlessness)

- **Lack evidence-based educational interventions**
- Symptom-focused interventions particularly rare
- **Systematic reviews – no carer educational interventions:**
  - for chronic respiratory disease
  - for breathlessness
- **New ERS Taskforce on carers of adults with chronic respiratory disease** – Alda Marques (University of Aveiro in Portugal) & Daisy Janssen (Maastricht)



# Learning about Breathlessness (LaB) study programme

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...to develop a resource to help support carers

## First needed to answer two questions

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- 1) What do carers want & need to learn about to help them support someone with breathlessness?
- 2) How do carers want to learn?

### Gathered the views of:

- carers & patients living with breathlessness due to COPD or cancer
- clinicians who support them



## We found...

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- Carers wanted and needed to learn
- Clinicians wanted to help carers learn
- Six key topics carers need to learn about
- Wide variation in how carers want to learn
- How we could meet varying learning preferences



## Six key topics carers need to learn about

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- 1) Understanding breathlessness
- 2) Anxiety, panic and breathlessness
- 3) Managing infections
- 4) Keeping active
- 5) Living positively
- 6) What to expect in the future



## How carers wanted to learn

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- Leaflet overload
- Face-to-face (one-to-one or group)
- Video or web-based
- Clinical experts & peer-carer experience
- Visual information (pictures & films)
  
- Learn with the patient (not every topic)
- Personalised or individualised
- Signposting to resources
  
- **Varied widely!**

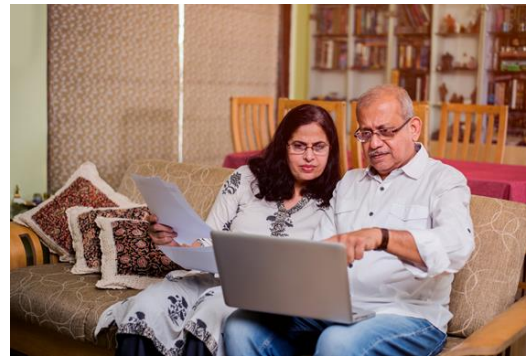


HOW?

# Web-based educational resource

## Accessible in four ways:

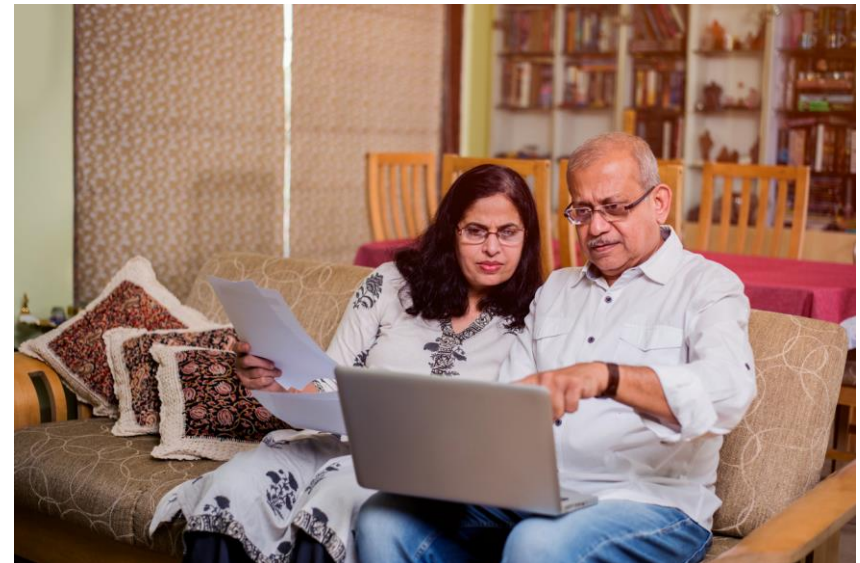
- 1) Self-accessed (or “prescribed”)
- 2) Peer-led support groups
- 3) Clinician-led groups
- 4) Clinician one-to-ones



## Website needed to...

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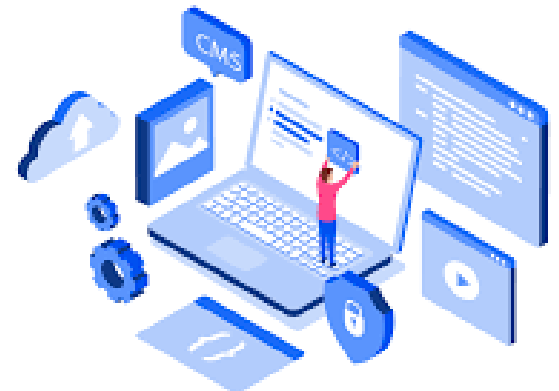
- Cover those six topics
- Have a menu (to choose what to look at)
- Written words & pictures
- Short film-clips (experts & peer carers)
  
- Downloadable leaflets
- Links to other resources
- Badged/ endorsed



## Developing the website

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- Worked with:
  - Carers – current carers & bereaved carers
  - Patients
  - Clinical experts
  - Website design experts



## Website feedback – from carers

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*“You can only **benefit from it**. [...] it’s important for people who are looking after their partner or wife or an elderly family member to understand what to do [...] and how to help as best as possible [...] **invaluable** for that”*

Carer 01-025

*“So it does offer something which the others don’t which is it is a **carer-focused** [...] it looks more at I suppose the social and relational aspects of being in this situation which is **useful**”*

Carer 01-014

## Website feedback – from clinicians

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*“It feels **very professional**... [it] makes you feel this is a **safe**, professional website that I can **trust**”*

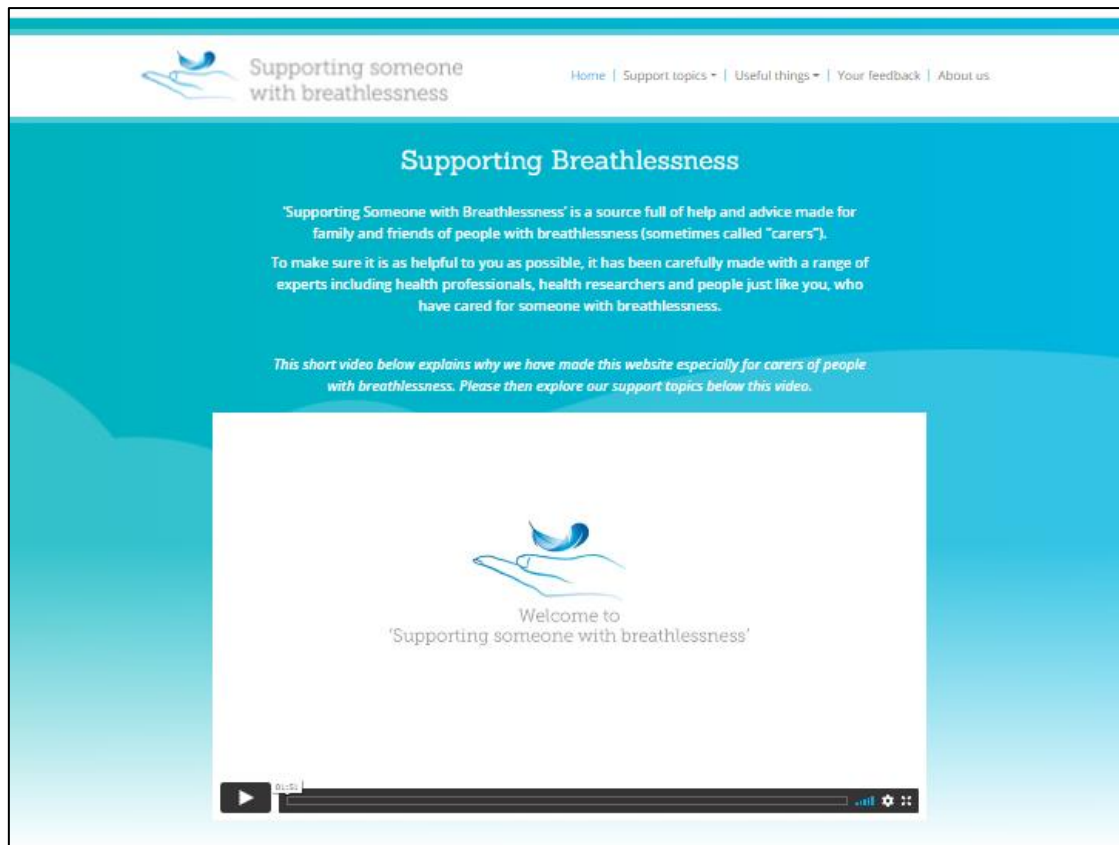
Cancer clinician 03-016

*“**I like the topics**. It’s not just managing the symptom but the stress, panic, keeping active and living a positive life”*

COPD clinician 03-002

# Supporting Someone with Breathlessness

[www.supporting-breathlessness.org.uk](http://www.supporting-breathlessness.org.uk)



# Scroll down the homepage...

## Support topics

Below are the main topics carers told us they want to know more about. Within each you can see, hear and read advice from experts, carers and patients.

To access this advice, click on the button above for the condition the person you support is living with: COPD or cancer – this will take you to the right information for their condition.



### Understanding breathlessness

Understand what causes breathlessness and try an activity to see what breathlessness can feel like

Cancer

COPD



### Stress, panic and breathlessness

Find out about the ways stress and panic can be unhelpful for breathlessness as well as some stress-busting ideas

Cancer

COPD



### Keeping active

Find out about how important it is for you and the patient to keep active and ideas to get you both moving

Cancer

COPD



### Living a fulfilling life

It's possible to live a fulfilling life with breathlessness – learn some ways to keep doing what is important for you and the patient

Cancer

COPD



### Managing infections

Learn some ways to help the patient avoid and manage infections

Cancer

COPD









### What to expect in the future

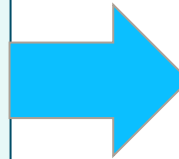
Find out what you and the patient might expect in the future with breathlessness and how to plan for it

Cancer

COPD

# Maps to the six topics

|  |  |  |
|--|--|--|
| <br><b>Understanding breathlessness</b><br>Understand what causes breathlessness and try an activity to see what breathlessness can feel like<br>Cancer COPD                                | <br><b>Stress, panic and breathlessness</b><br>Find out about the ways stress and panic can be unhelpful for breathlessness as well as some stress-busting ideas<br>Cancer COPD | <br><b>Keeping active</b><br>Find out about how important it is for you and the patient to keep active and ideas to get you both moving<br>Cancer COPD            |
| <br><b>Living a fulfilling life</b><br>It's possible to live a fulfilling life with breathlessness – learn some ways to keep doing what is important for you and the patient<br>Cancer COPD | <br><b>Managing infections</b><br>Learn some ways to help the patient avoid and manage infections<br>Cancer COPD  | <br><b>What to expect in the future</b><br>Find out what you and the patient might expect in the future with breathlessness and how to plan for it<br>Cancer COPD |



**LaB1 – 6 key topics**



- 1) Understanding breathlessness
- 2) Anxiety, panic and breathlessness
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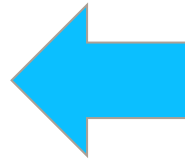
Farquhar et al. [PLoS ONE](#) 2017 May 5;12(5):e0177081




## Maps to how carers want to learn

- ✓ Has a menu (to choose what to look at)
- ✓ Written words & pictures
- ✓ Short film-clips (experts & peer carers)
- ✓ Downloadable leaflets
- ✓ Links to other resources
- ✓ Badged/ endorsed


- 1) Self-accessed by the carer
- 2) Peer-led support groups
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### How carers wanted to learn

- Leaflet overload
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# Click on a topic

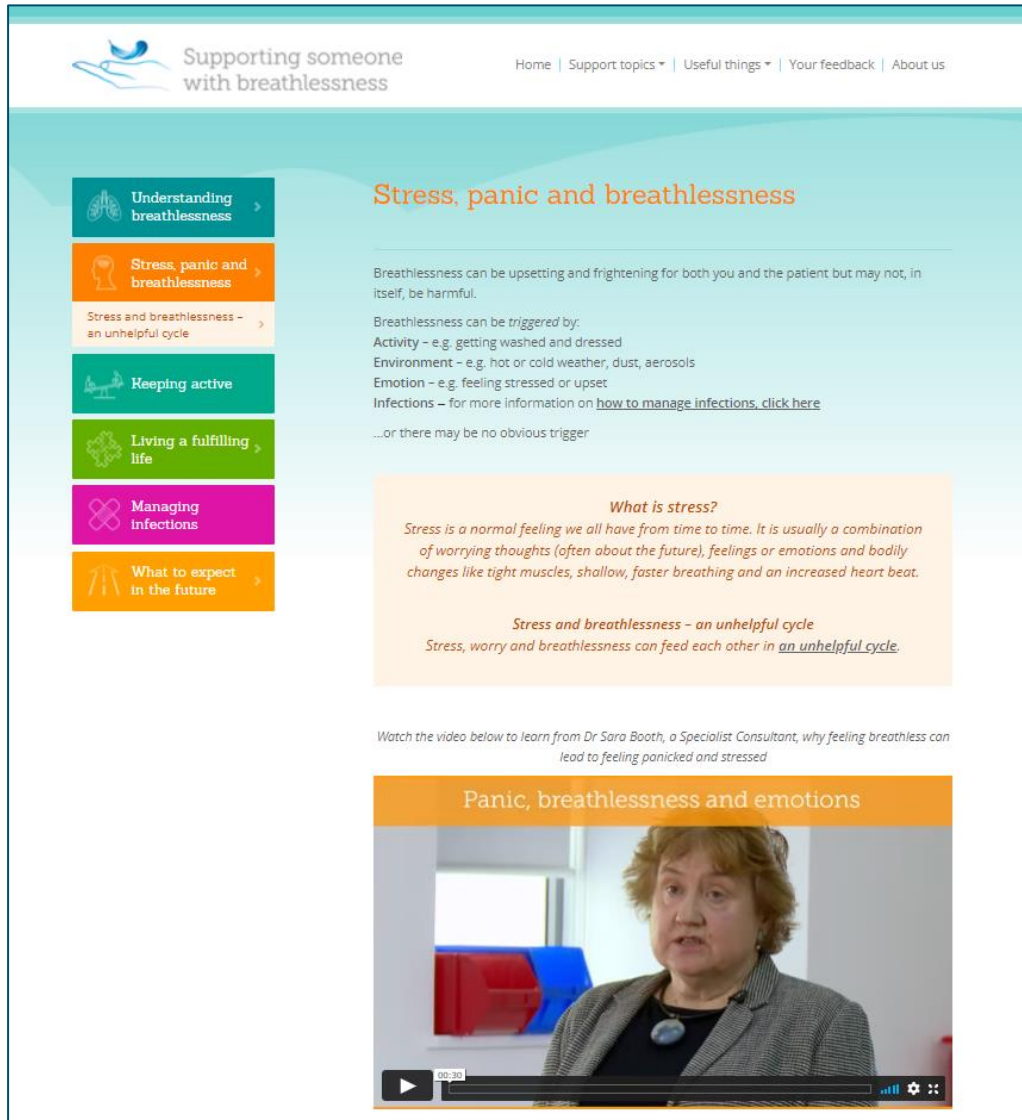
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|  |   |  |
|--|---|--|
|  <h4>Understanding breathlessness</h4> <p>Understand what causes breathlessness and try an activity to see what breathlessness can feel like</p> <p>Cancer COPD</p>                                 |  <h4>Stress, panic and breathlessness</h4> <p>Find out about the ways stress and panic can be unhelpful for breathlessness as well as some stress-busting ideas</p> <p>Cancer COPD</p> |  <h4>Keeping active</h4> <p>Find out about how important it is for you and the patient to keep active and ideas to get you both moving</p> <p>Cancer COPD</p>             |
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# Each topic has words, pictures & films



Supporting someone with breathlessness

Home | Support topics ▾ | Useful things ▾ | Your feedback | About us

- Understanding breathlessness
- Stress, panic and breathlessness**
- Stress and breathlessness – an unhelpful cycle
- Keeping active
- Living a fulfilling life
- Managing infections
- What to expect in the future

## Stress, panic and breathlessness

Breathlessness can be upsetting and frightening for both you and the patient but may not, in itself, be harmful.

Breathlessness can be *triggered* by:

- Activity – e.g. getting washed and dressed
- Environment – e.g. hot or cold weather, dust, aerosols
- Emotion – e.g. feeling stressed or upset
- Infections – for more information on [how to manage infections](#), [click here](#)

...or there may be no obvious trigger

**What is stress?**


*Stress is a normal feeling we all have from time to time. It is usually a combination of worrying thoughts (often about the future), feelings or emotions and bodily changes like tight muscles, shallow, faster breathing and an increased heart beat.*

**Stress and breathlessness – an unhelpful cycle**

*Stress, worry and breathlessness can feed each other in [an unhelpful cycle](#).*

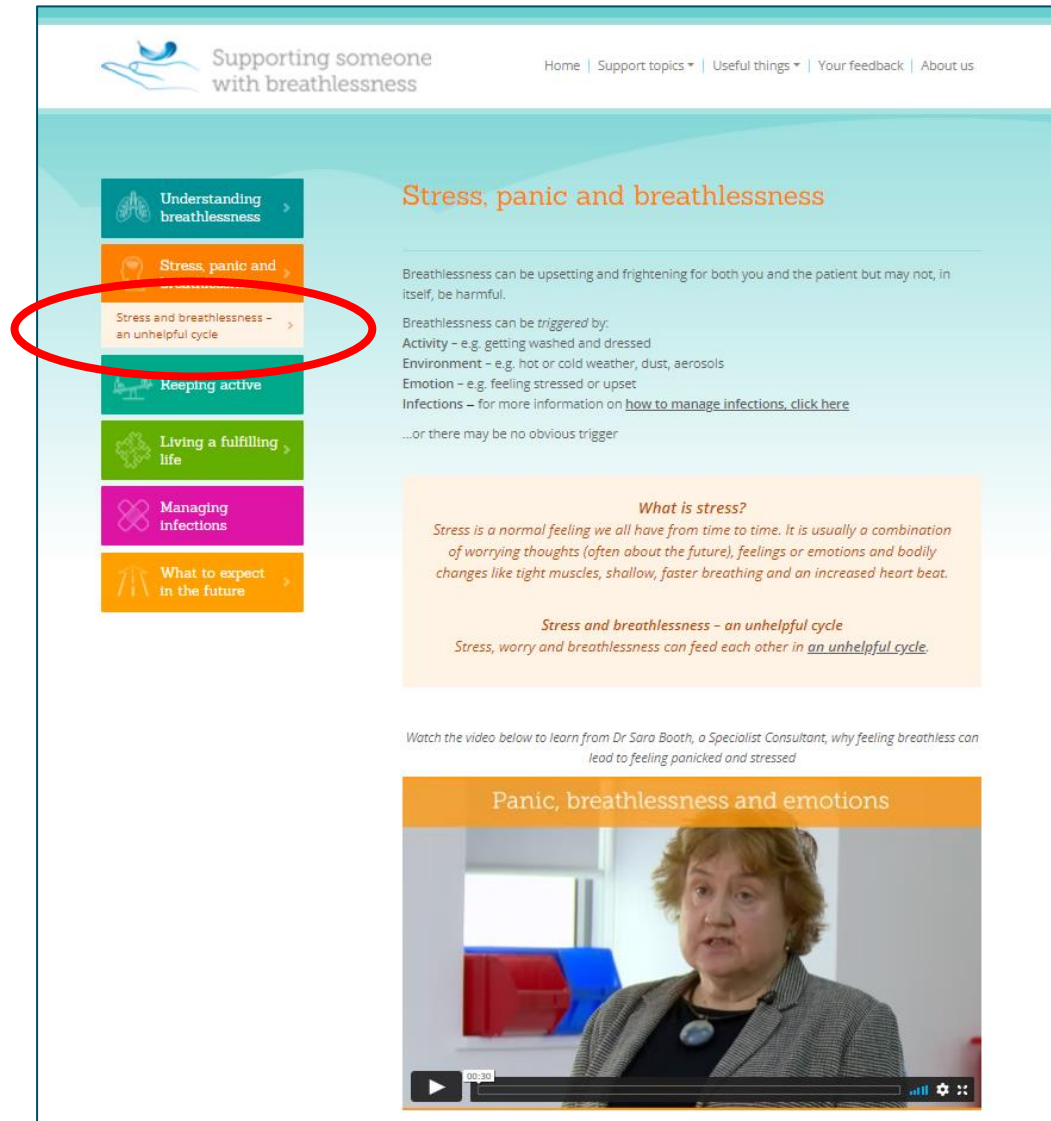
Watch the video below to learn from Dr Sara Booth, a Specialist Consultant, why feeling breathless can lead to feeling panicked and stressed

### Panic, breathlessness and emotions



00:30

# Inside each topic are sub-topics...



Supporting someone with breathlessness

Home | Support topics ▾ | Useful things ▾ | Your feedback | About us

Understanding breathlessness >

Stress, panic and >

Stress and breathlessness - an unhelpful cycle >

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### Stress and breathlessness - an unhelpful cycle


*Stress, worry and breathlessness can feed each other in [an unhelpful cycle](#).*

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## Stress and breathlessness – an unhelpful cycle

Stress is a common feeling we all have from time to time. It is impossible to take away stress completely, but there are lots of [ways to manage stress levels](#) when they start to get out of hand.

Often we become stressed when we think about things that may happen in the future. This worry can then cause changes in our bodies like tense or tight muscles, an upset stomach, dizziness and shallow, faster breathing.

It is common for people with health problems and their carers to feel more stressed than other people. This is because they are faced with extra challenges, day-to-day.

Stress can be particularly unhelpful for breathlessness because together they can create a vicious cycle, feeding one another.



```

graph TD
    A((Signs of breathlessness)) --> B((Stressful thoughts "Is this serious?"))
    B --> C((Changes in the body: Shallow breathing, Tight muscles))
    C --> D((Breathlessness gets worse))
    D --> E((Stress gets worse "It's getting worse! This MUST be serious!"))
    E --> A
          
```

**Picture this . . .**  
Chris notices he is feeling breathless

## Topics include film clips of...



clinical experts

peer carers



...and film clips of...



patients & carers

- demonstrating strategies
- discussing topics



# “Useful things” page – leaflets



Supporting someone  
with breathlessness

Home | Support topics ▾ | **Useful things ▾** | Your feedback | About us



We hope you've found this website a useful source of help and advice. It was carefully made with a range of experts including health professionals, health researchers and experts by experience – people who, just like you, have cared for someone with breathlessness.

## Carer feedback:

*"You can only benefit from it. It's important for people who are looking after their partner or wife or an elderly family member to understand what to do...it's invaluable for that"*  
- 'Sarah', carer

## Printable topic pages

Here you can find printable sheets with the information from each of the support topics on this website. You can open and read these information sheets and save them on your computer or print them by pressing on the document names below.

### Support topics for breathlessness due to COPD

[Understanding breathlessness in COPD \(PDF 348KB\): Click here](#)

[Stress, panic and breathlessness \(PDF 426KB\): Click here](#)

[Ways to ease breathlessness \(PDF 478KB\): Click here](#)

[Keeping active \(PDF 700KB\): Click here](#)

[Living a fulfilling life \(PDF 423KB\): Click here](#)

[Managing infections \(PDF 600KB\): Click here](#)

[Looking after your own health \(PDF 404KB\): Click here](#)

[As the patient becomes more unwell – COPD \(PDF 622KB\): Click here](#)

[Accessing care and support – COPD \(PDF 425KB\): Click here](#)

[Talking to the healthcare team \(PDF 484 KB\): Click here](#)

[When someone dies \(PDF 499KB\): Click here](#)

# “Useful things” page – links to other sites



Supporting someone  
with breathlessness

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*"You can only benefit from it. It's important for people who are looking after their partner or wife or an elderly family member to understand what to do, it's*

## Links and resources

The below organisations have other useful information for carers and patients living with breathlessness. Click on the organisation names to be taken to their websites.

### General respiratory links and resources

[British Lung Foundation](#)

[Breathlessness Intervention Service \(BIS\)](#)

[Patient UK](#)

[Marie Curie – 'Managing breathlessness' booklet](#)

### Carer links and resources

[Carers UK](#)

[Marie Curie – 'Managing breathlessness' booklet](#)

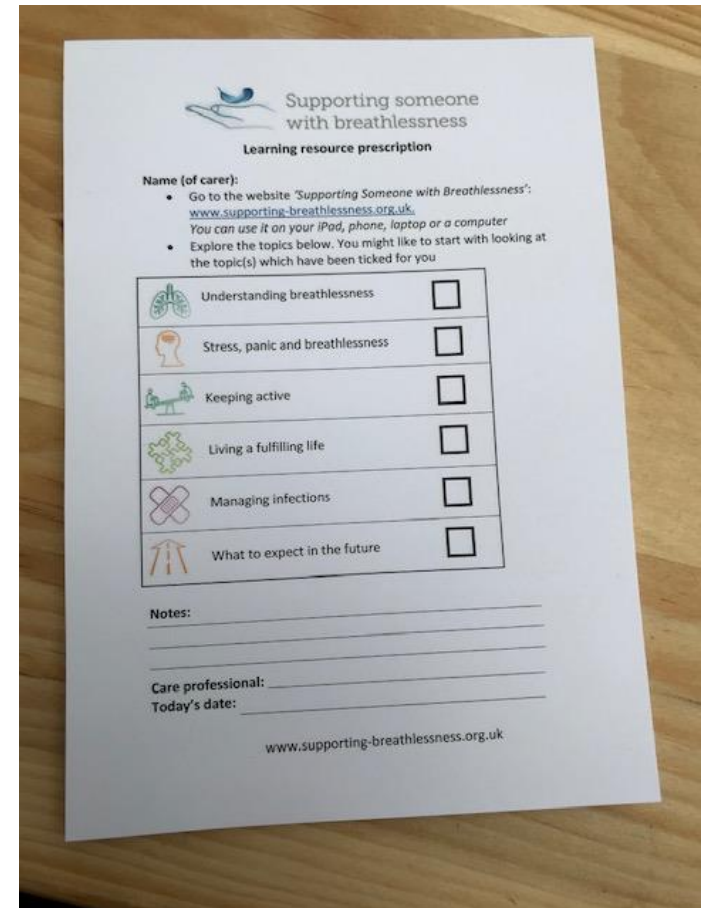
### COPD links and resources

[Living well with COPD](#)

[Patient.co.uk](#)

# Promotional materials

- Carers & patients suggested:
  - Promotional cards
  - Mock “prescription pads”
- Clinicians can:
  - Download from website
  - Contact me for printed ones  
*(recent re-stock!)*



## National & international endorsement

- Website linked from:

- British Lung Foundation



- British Heart Foundation



- Royal College of General Practitioners



- Queen's Nursing Institute



- NHS website 

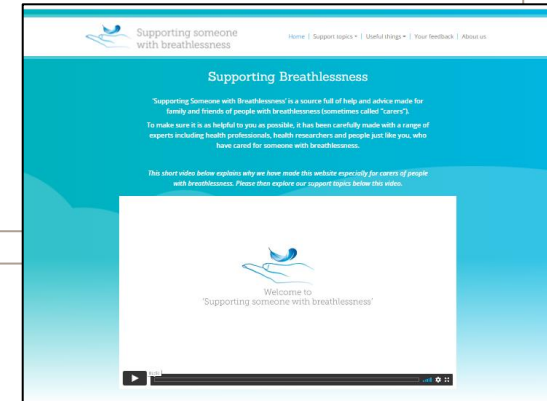
- Website material adapted for:

- Australia & New Zealand



# Learning about Breathlessness: Funder Acknowledgement

- LaB1: Dimbleby Cancer Care



- LaB2: NIHR Research for Patient Benefit

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**NIHR** | Applied Research Collaboration  
East of England

# Learning about Breathlessness: Programme acknowledgements

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- **Participants:**
  - patients, carers & health care professionals
- **Facilitators:**
  - CRN-Eastern, clinical recruiting sites & support groups
  - NHS South Norfolk CCG
- **Carer Advisory Group (PPI)**
- **Project team (LaB1 + LaB2):**
  - Sylvia Barnes (LaB2 SRA), Clarissa Penfold (LaB1 SRA), Roberta Lovick, Dr Sara Booth, Dr Gail Ewing, Sophie Howson, Dr Ravi Mahadeva, Dr Ingrid Muller, Dr Kate Greenwell, Dr John Benson, Dr David Gilligan, Prof Chris Todd



## Programme team

Prof Morag Farquhar (PI)

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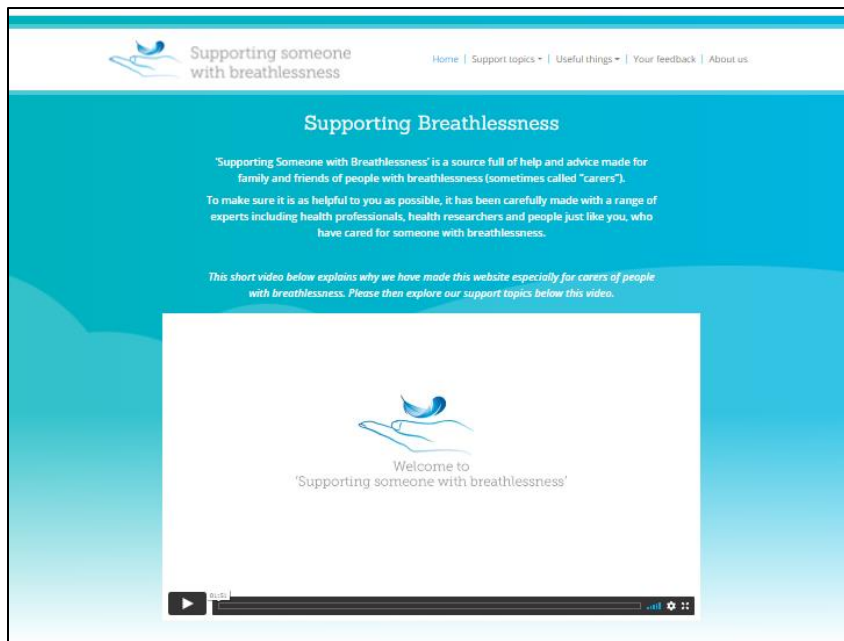
Dr John Benson

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Prof Chris Todd



# Thank you!



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## LaB programme references

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- Farquhar M et al. Six key topics informal carers of patients with breathlessness in advanced disease want to learn about and why: MRC Phase I study to inform an educational intervention. *PLoS ONE* 2017 May 5;12(5): e0177081
- Ewing et al. Clinicians' views of educational interventions for carers of patients with breathlessness due to advanced disease: findings from an online survey. *Jnl Pain & Symptom Manage* 2017;55(2):265-271
- Farquhar M et al. What are the key elements of educational interventions for lay carers of patients with advanced disease? A systematic literature search and narrative review of structural components, processes and modes of delivery. *Jnl Pain & Symptom Manage* 2016;52(1):117-30