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**What do informal carers of people living with  
breathlessness in advanced disease want to learn  
*“What to Expect in the Future”*?**



**RCN International Research Conference, 4th Sept 2019, Sheffield  
Morag Farquhar, Gail Ewing, Sylvia Barnes**



**@LaB2\_Study**

# Breathlessness

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- **Common in advanced cancer & non-cancer conditions**
  - chronic obstructive pulmonary disease (COPD)
  - heart failure
  - renal & neurological conditions
- **Almost as common as pain**
  - fewer interventions/ resources
  - less public understanding
- **Frightening & disabling**
- **Difficult to manage**





## Supporting carers

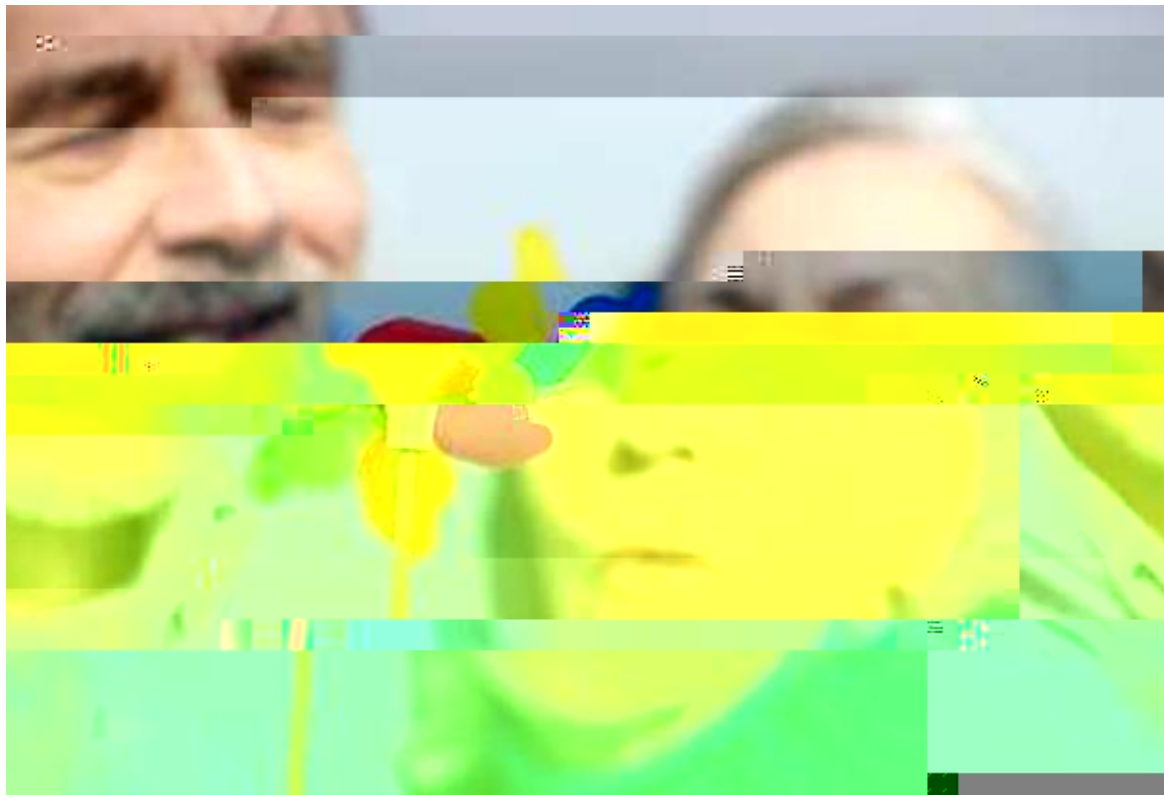
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- **Lack evidence-based educational interventions carers**
- **Symptom-focused interventions particularly rare**
- **Systematic reviews no educational interventions:**
  - for carers in chronic respiratory disease
  - for carers in breathlessness



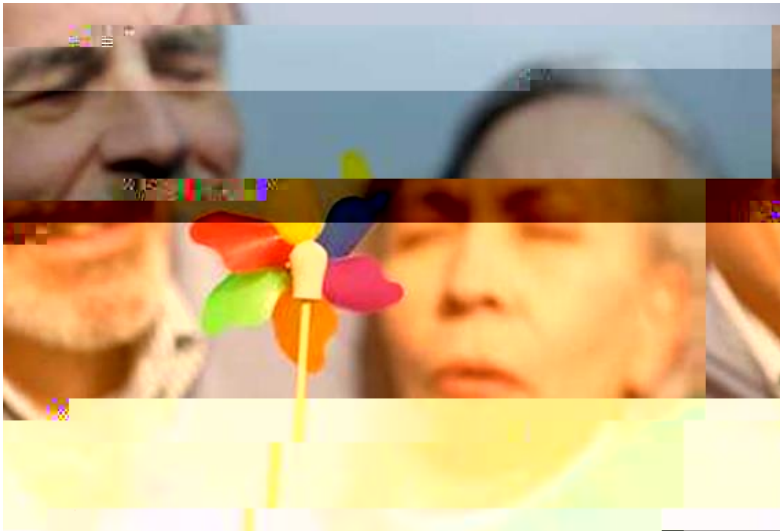
# Learning about Breathlessness (LaB) study programme

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# Learning about Breathlessness 1

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## Aim of LaB1:

To find out what carers want to learn about supporting someone with breathlessness and how they want to learn



- 
- **Educational need & desire of carers**
  - **Six key topics they want to learn about**
  - **Wide variation in how carers wanted to learn**
  - **How we could meet varying learning preferences**
  -



## LaB1 6 key topics

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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

[Farquhar et al, 2017]





# LaB1 How carers wanted to learn

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## LaB1 Web-based educational platform

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### Accessible in four ways:

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

## LaB1 Web-based educational platform

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### Accessible in four ways:

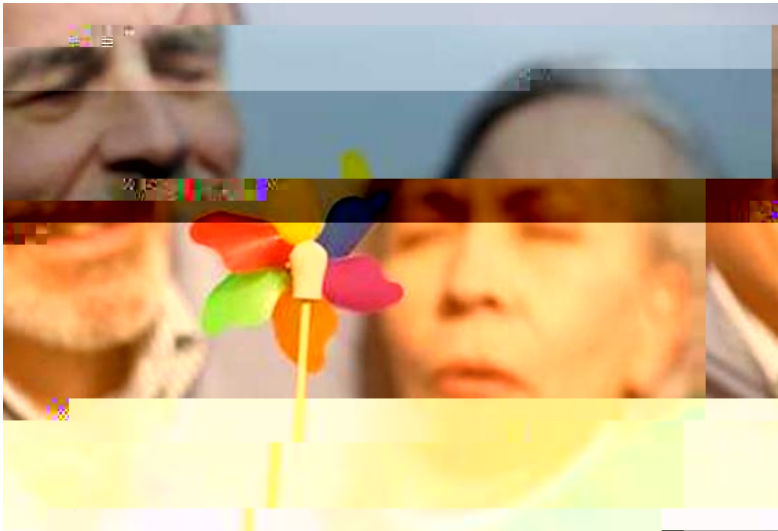
- 1) Self-accessed (or “prescribed”)
- 2) Peer-led support groups
- 3) Clinician-led groups
- 4) Clinician one-to-ones

**Requirements:** cover the 6 topics; menu-driven; text, pictures & short film-clips (experts & peer carers); downloadable leaflets; links to other resources; badged/endorsed



## Learning about Breathlessness 2

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### Aim of LaB2:

To develop a web-based, educational intervention on breathlessness for informal carers of patients with advanced disease

FUNDED BY





## Bereaved carers recruitment

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- Multi-setting recruitment strategy:
  - primary care, secondary care (palliative care, respiratory, oncology), hospices and support groups
- 2 focus groups and 6 x 1:1 interviews
- 12 bereaved carers (6-9 months post death)
  - cancer carers = 6
  - COPD carers = 6
- Range of different caring experiences, relationships and stories





# Results

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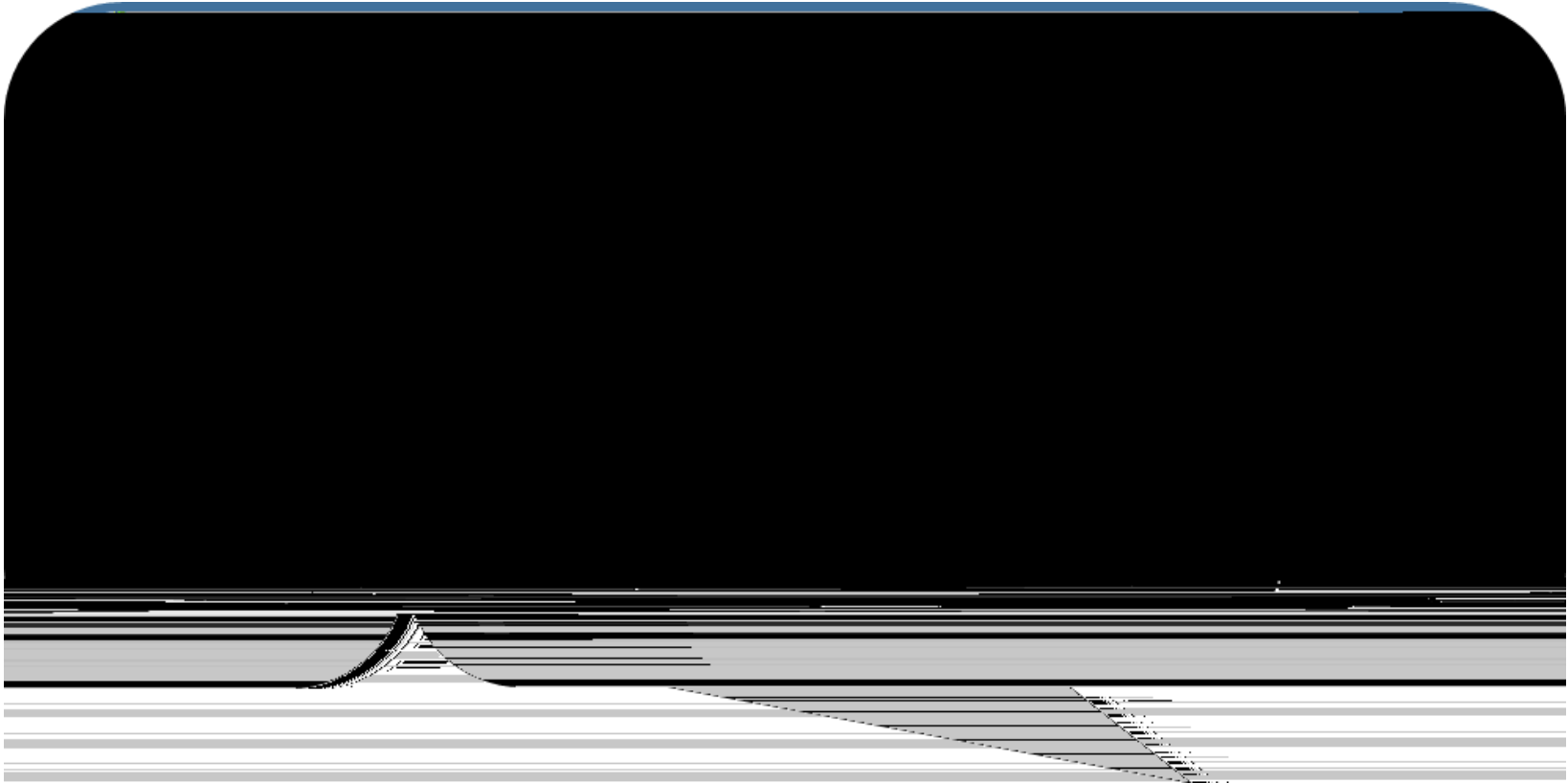
## Five key areas:

- 1) Coping with symptom changes as the patient's condition worsened
- 2) Discussing "the future" with others
- 3) Accessing care and support
- 4) Administrative tasks
- 5) Coping with emotions after the patient's death

# 1) Coping with symptom changes as the

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- Surprised and unprepared for changes in symptoms
- Denial and hope
- Understanding the dying process
- Practical advice and planning ahead
- Tension between the needs of carers and patients

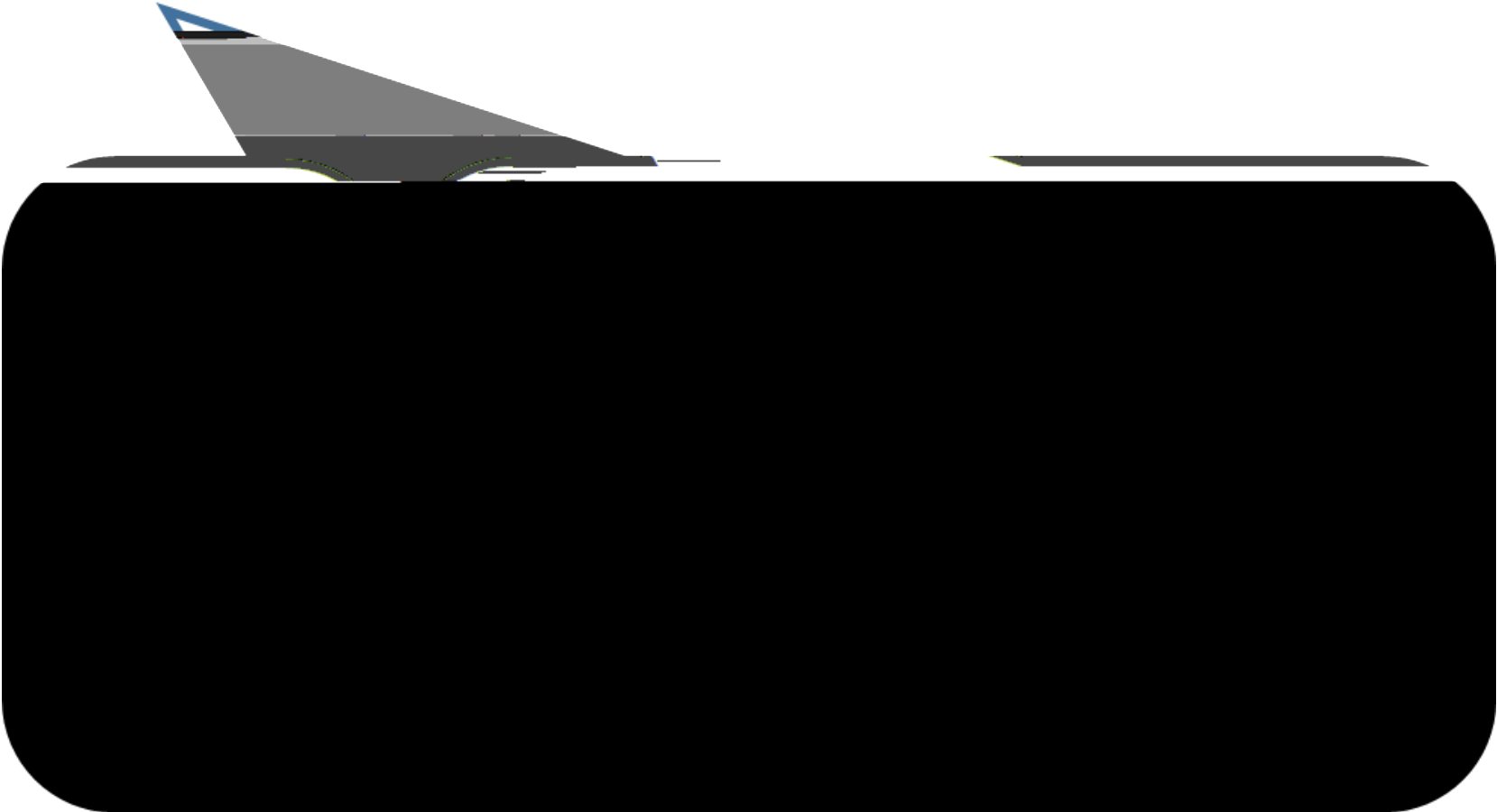


- 
- Wider social issue, of people generally being unable to discuss death – making their grieving even more difficult









## 4) Administrative tasks

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- Unprepared for the amount of practical, administrative jobs that needed to be done once their patient had died

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[03-010, Cancer]

- Helpful to have arrangements organised together with the patient, in advance:

- 

*directors, got the plan of everything, there was very*

[01-008, Cancer]



## Administrative tools for registering the

death)

*“Maybe encouraging people to have*

*...word with solicitors, legal advisors, ...*

*...have ...*

*ossible” – 03-010, Cancer*



## 5) Coping with emotions after the

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- Struggled with range of difficult emotions after the death:
  - Shock
  - Guilt
  - Sadness
  - Anger

- 

[01-017, COPD]

- 

[04-010, Cancer]



## Viewing the topic with the patient

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- *up to the individual. I think they will make it clear if  
might play on their mind and make them upset*  
[03-006 COPD]
- *might*  
*have opened her up to talk to me more  
for me to broach the subject*  
[01-017 COPD]
- *how helpful it would be for me*  
[01-008 Cancer]

## Draft topic content review

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**Bereaved carers: Jan-Feb 2019 (focus groups/interviews)**



**Review with Carer Advisory Group (PPI)**



**Review with Study Advisory Group**



**Current carers: March 2019 (workshops)**

## Refined topic content review

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**Bereaved carers:** Jan-Feb 2019 (focus groups/interviews)

# All six topics

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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**





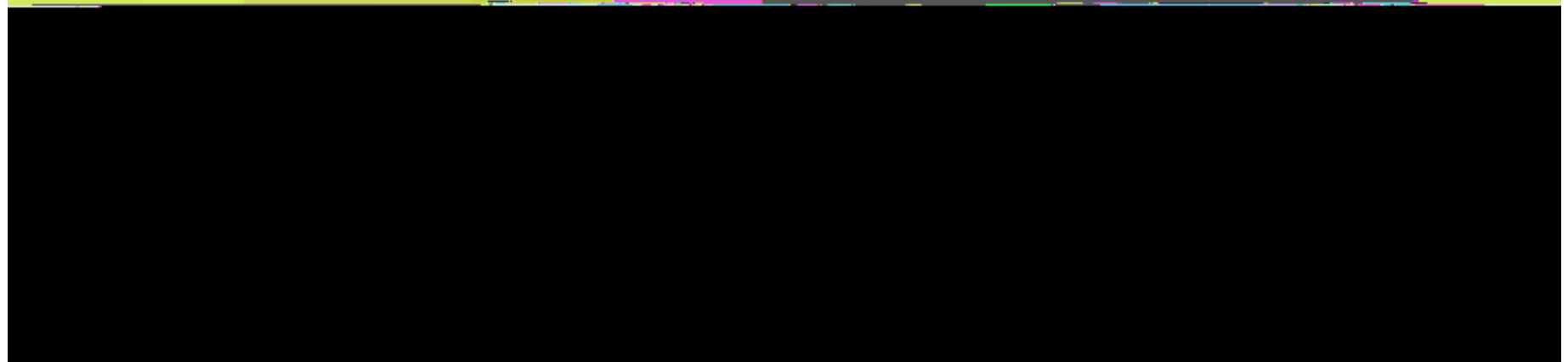
# What's new in 'Community'

Breathlessness is a source for help and advice made for people with breathlessness from a range of people.

Our new website has been designed to help you find the support you need.

Supporting Someone with Breathlessness  
family and friends of people

To make sure it is as helpful as possible, it has been carefully made with a range of experts including health professionals, researchers and experts by experience - people who just like you have cared for someone with breathlessness.





Relaxation techniques, such as meditation, can help reduce stress and improve breathing.

Understanding what causes breathlessness can help you and your doctor decide on the best treatment for you.

Understanding what causes breathlessness can help you and your doctor decide on the best treatment for you.

### Understanding

#### breathlessness

### Other signs and

#### symptoms

Understand what causes

### Keeping

#### active

Find out about the ways stressed

### Prevention

#### tips

Find out about how important it is

### Looking a

#### head

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

### Managing

#### it

### What to expect

#### from

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

### Prevention

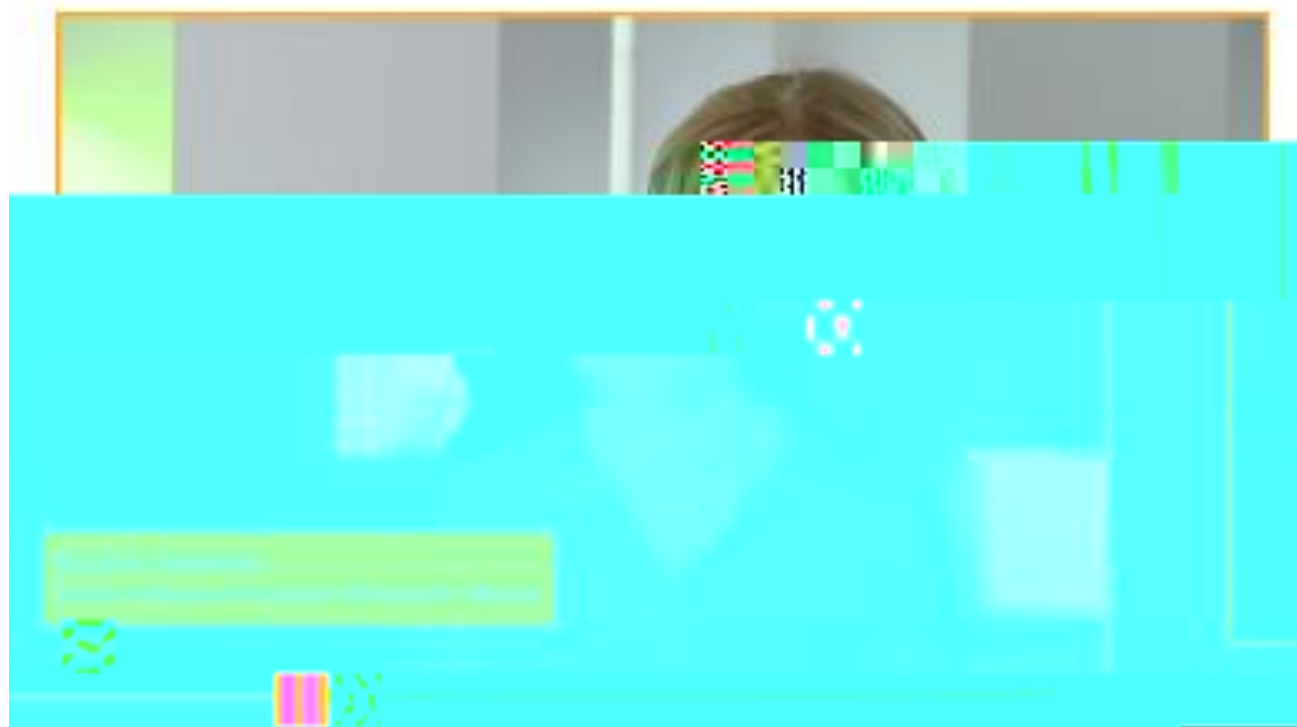
#### tips

Learn some ways to help the patient avoid and manage infections

# Supporting Someone with Breathlessness

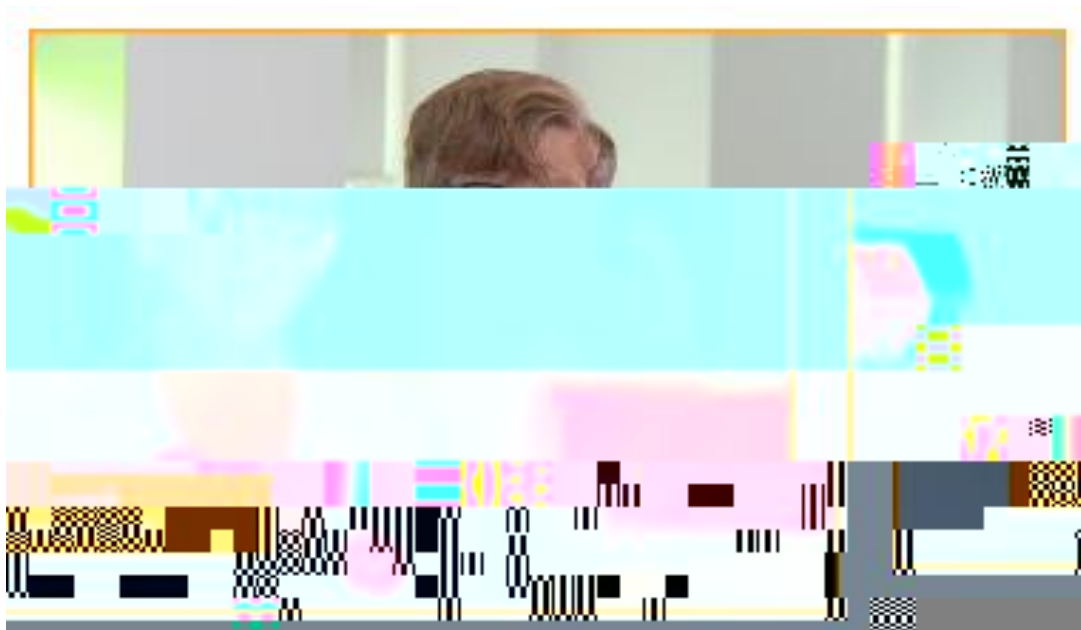
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Clinical experts



# Supporting Someone with Breathlessness

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Peer carers



Clinical experts



# Supporting Someone with Breathlessness

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Peer carers

- Demonstrating strategies



# Supporting Someone with Breathlessness

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## Peer carers

- Demonstrating strategies
- Discussing topics



## Next steps

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- **Think-aloud interviews on the prototype website:**
  - Carers on own
  - Carers and patients together
  - Clinicians who support carers
- **Website refinement**
- **Pilot the four access routes:**
  - Self-accessed
  - Peer-led support groups
  - Clinician-led groups
  - Clinician one-to-ones

# Conclusion

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# Photo credits

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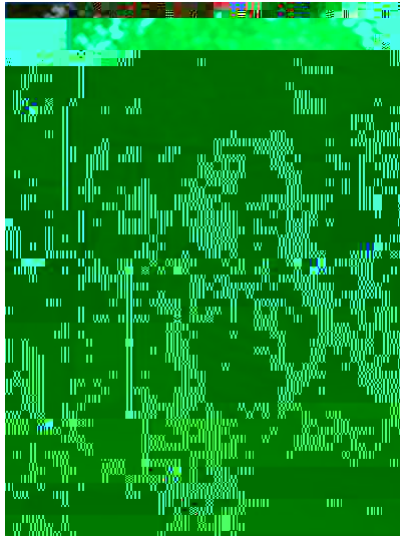
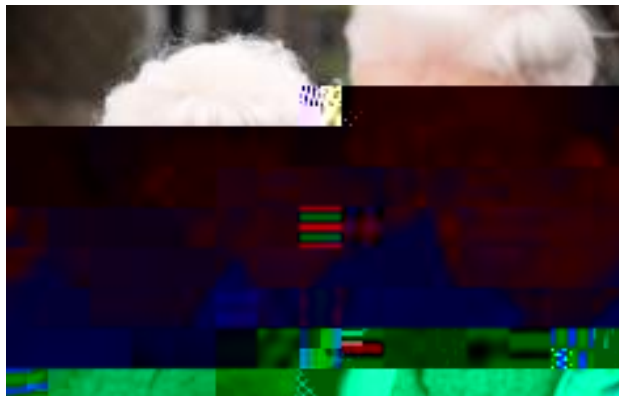
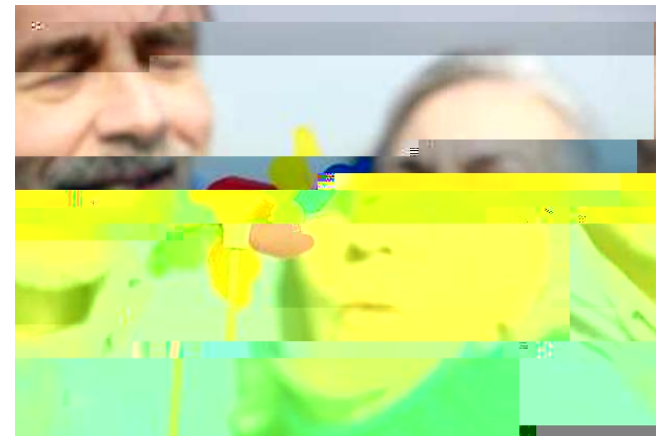


Photo 44203531 © Nuno Monteiro - Dreamstime.com



<https://smartfishnutrition.com/health-care/copd/>



Credit:Getty

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# Thank you

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@LaB2\_Study



SNAP.team@uea.ac.uk

S.Barnes@uea.ac.uk

M.Farquhar@uea.ac.uk

