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



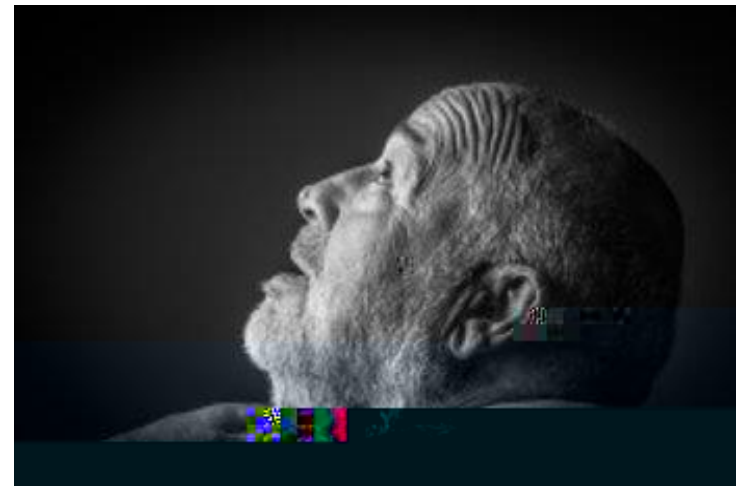
**RCN International Research Conference, 4th Sept 2019, Sheffield
Morag Farquhar, Gail Ewing, Sylvia Barnes**



@LaB2_Study

Breathlessness

- **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**

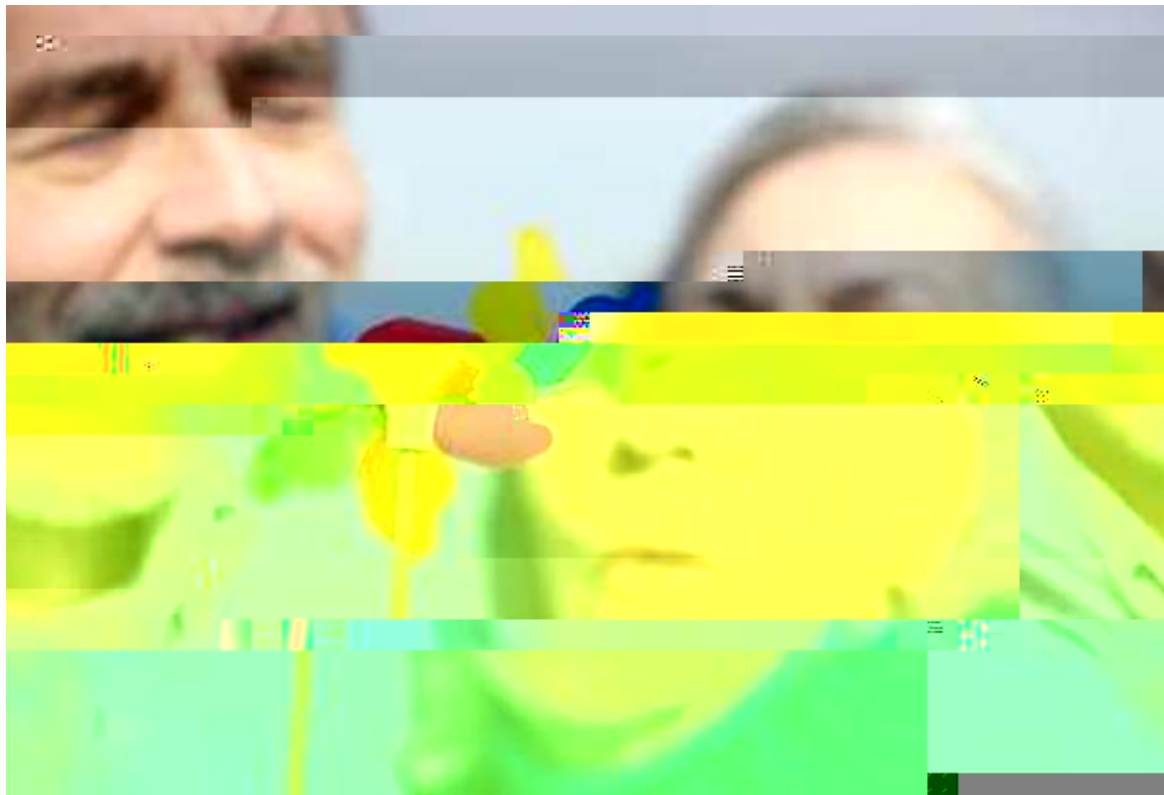


Supporting carers

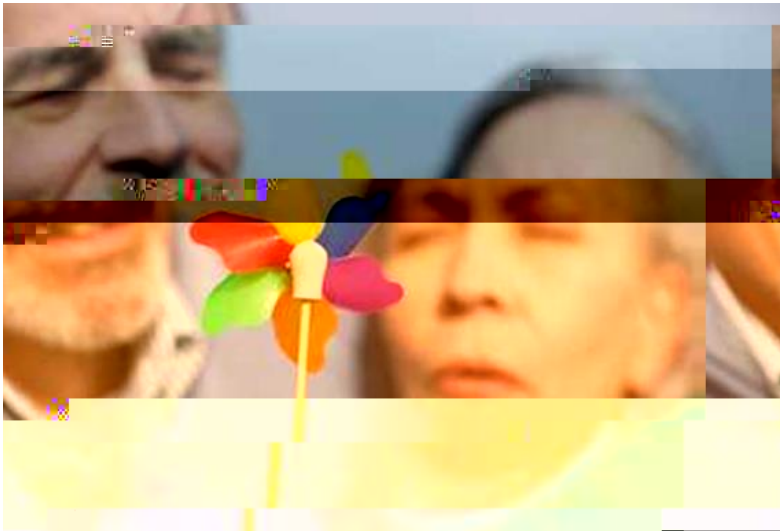
- **Lack evidence-based educational interventions carers**
- **Symptom-focused interventions particularly rare**
- **Systematic reviews no educational interventions:**
 - for carers in chronic respiratory disease
 - for carers in breathlessness



Learning about Breathlessness (LaB) study programme



Learning about Breathlessness 1



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

- 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



LaB1 Web-based educational platform

Accessible in four ways:

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

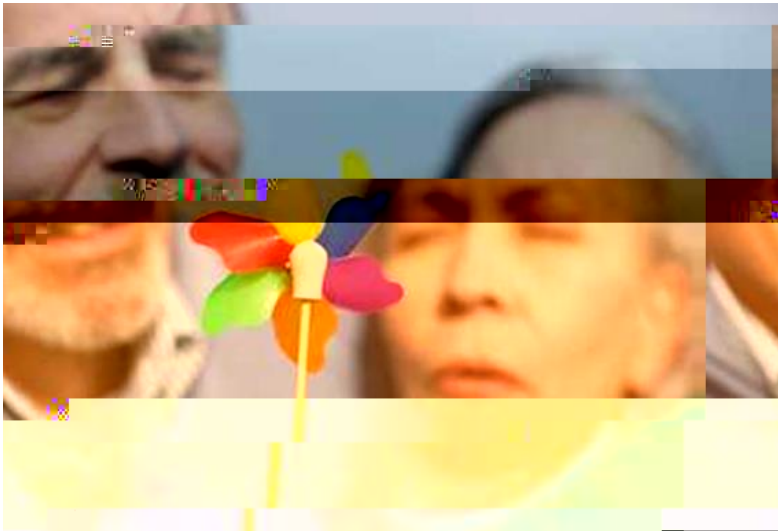
LaB1 Web-based educational platform

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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



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

- 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

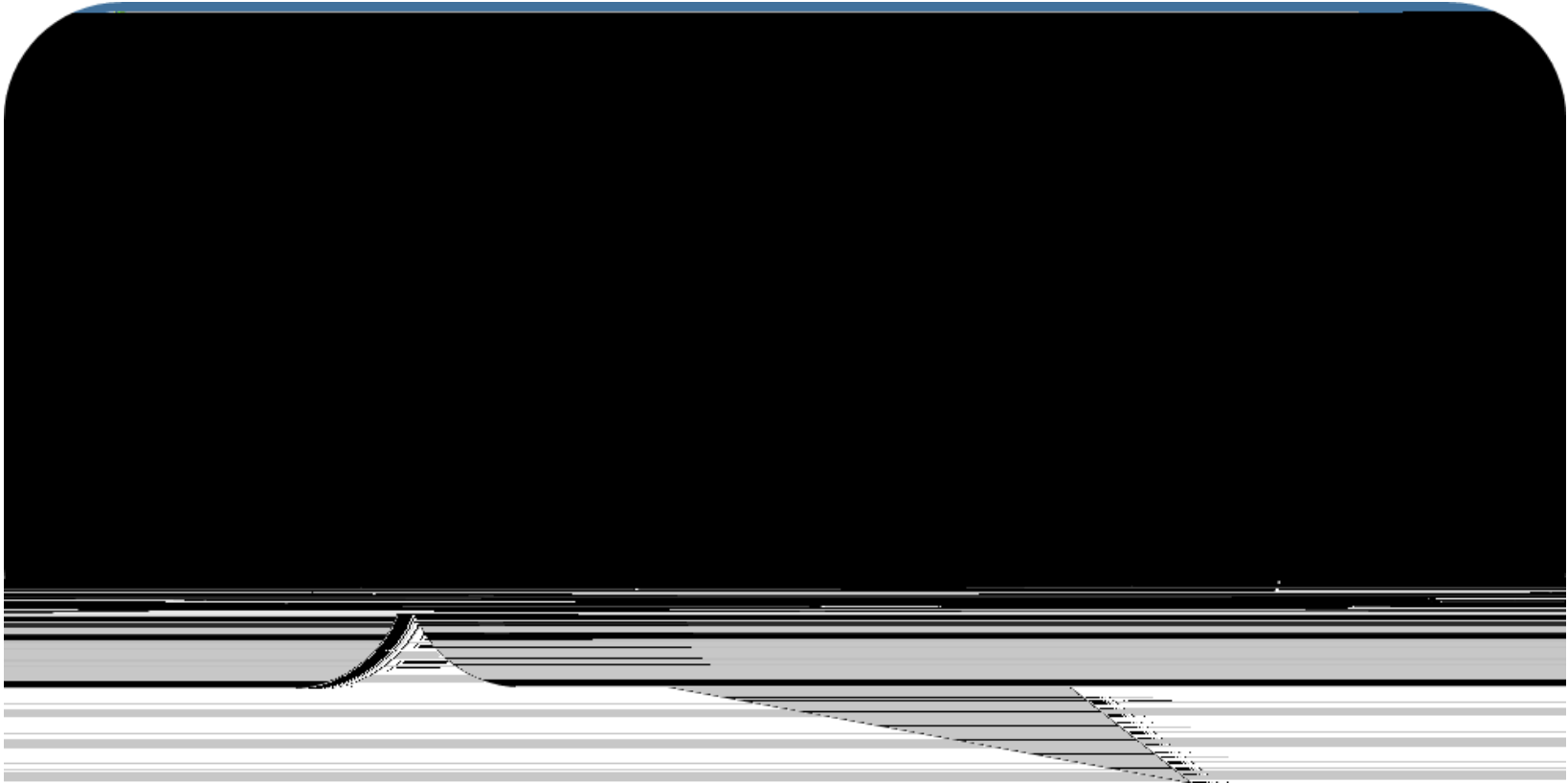
Results

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

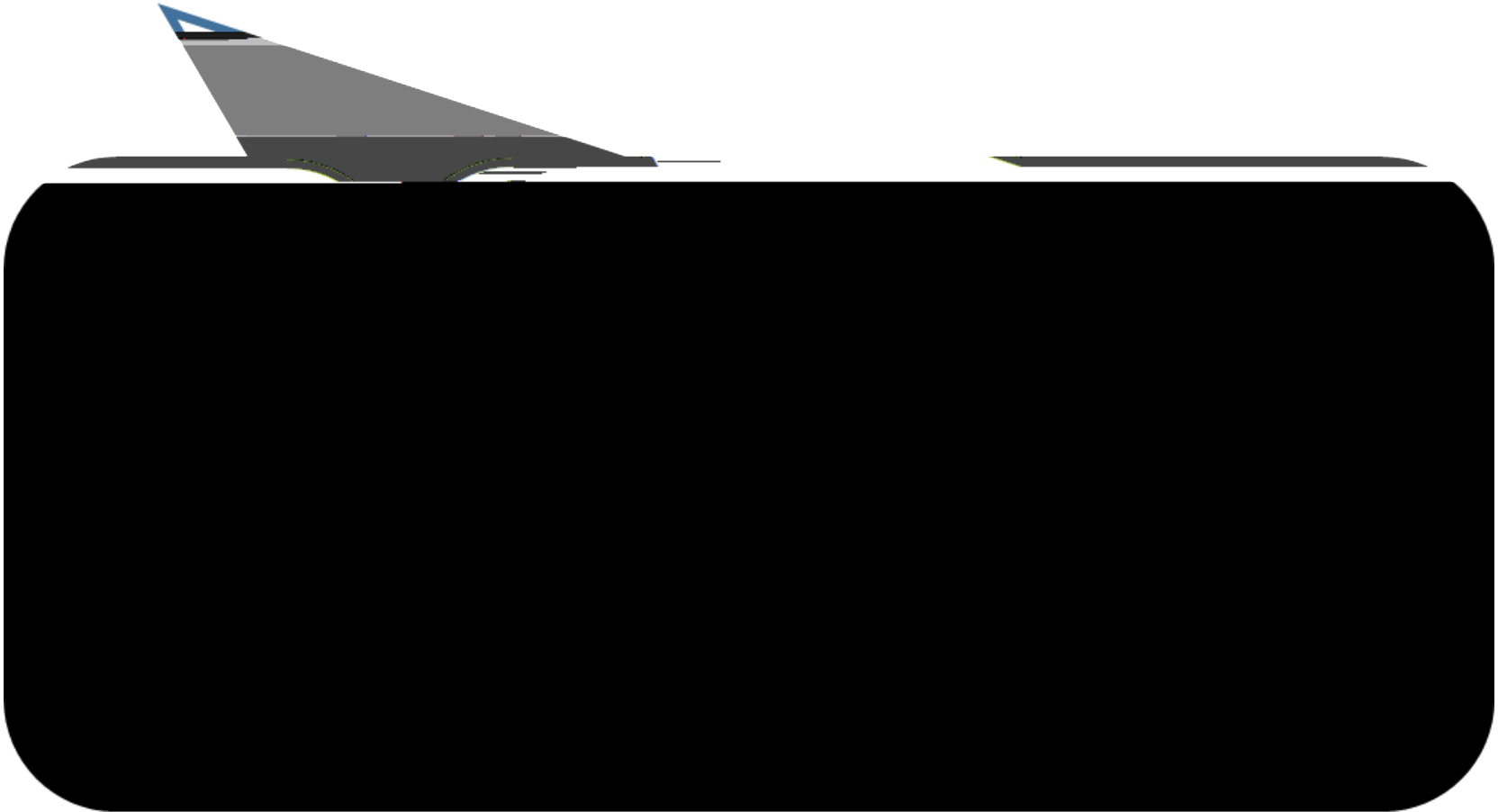
1) Coping with symptom changes as the

- 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

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

-

[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

access to legal services, legal education,

possible” – 07-010, Cancer

5) Coping with emotions after the

- 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

- *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

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

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

All six topics

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 of help and advice made for family and friends of people with breathlessness.

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.



Follow up the main section, or go to the top of the page to see the full page.

Learn some ways to help the patient avoid and manage infections

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

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



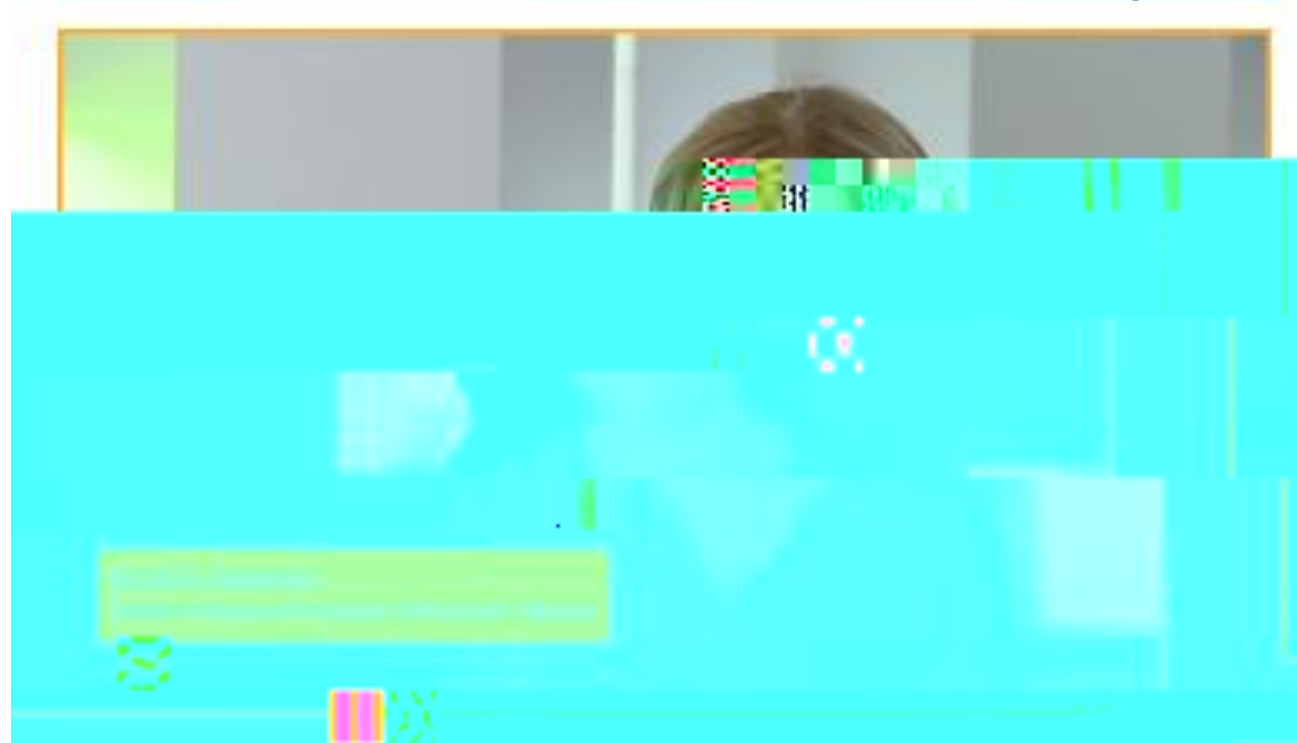
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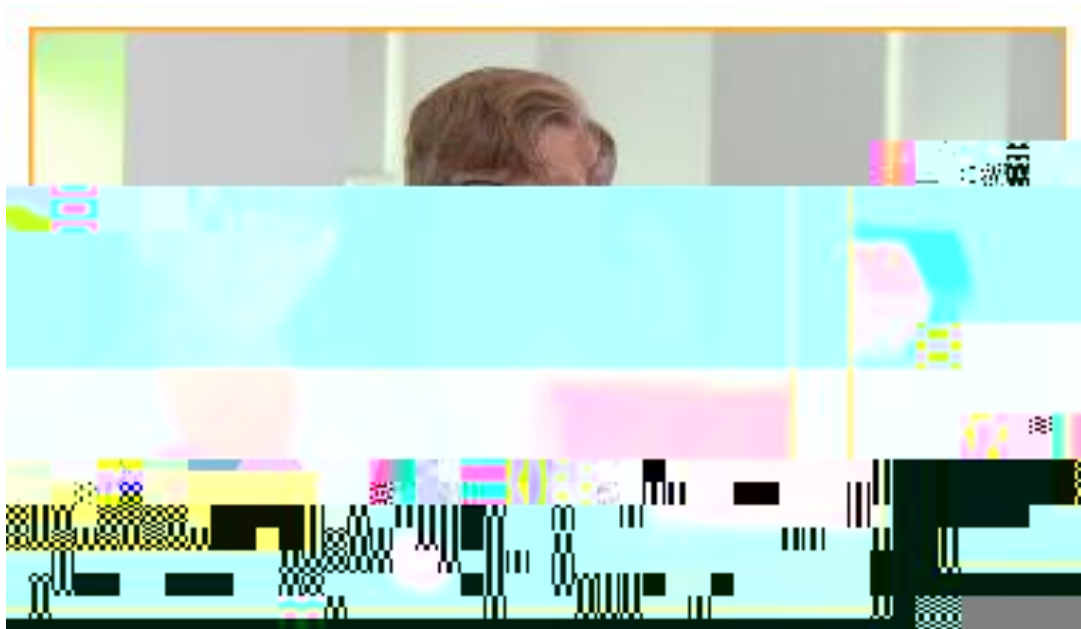
It's possible to live a fulfilling life with breathlessness – learn some ways to keep doing what is important for you and the patient

Supporting Someone with Breathlessness

Clinical experts



Supporting Someone with Breathlessness



Peer carers



Clinical experts



Supporting Someone with Breathlessness

Peer carers

- Demonstrating strategies



Supporting Someone with Breathlessness



Peer carers

- Demonstrating strategies
- Discussing topics



Next steps

- **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

Photo credits

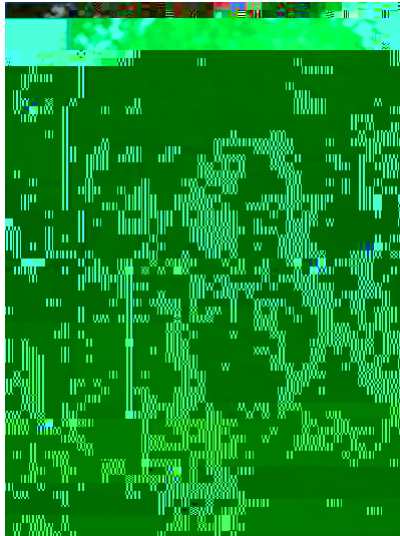
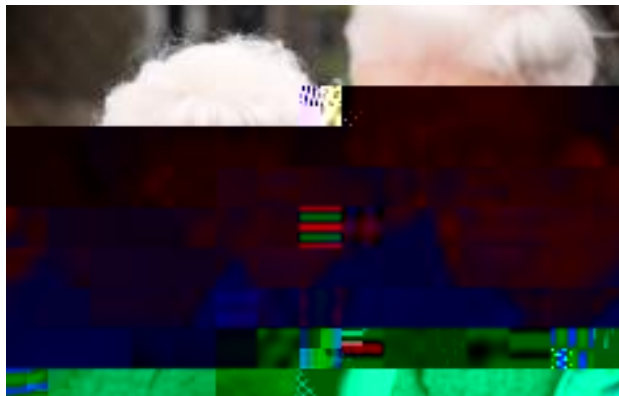
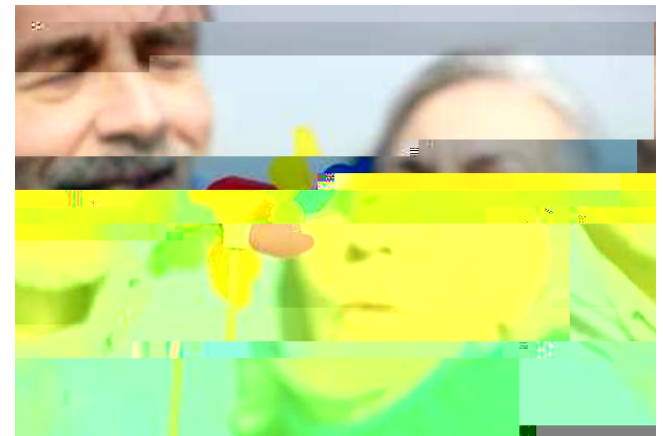


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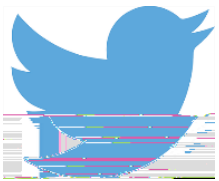


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Thank you



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