

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



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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**



Impact of breathlessness on carers

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



Supporting carers

- **Lack evidence-based educational interventions for 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

LaB1 identified...

- **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**
- **Clinicians' appetite for an intervention**



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**



LaB1 – How carers wanted to learn

- **Varied!**
 - **Leaflet overload**
 - **Face-to-face, group, video or web-based**
 - **Clinical experts & peer-carer experience (tips)**
 - **Visual information**
 - **Learning with the patient (not every topic)**
 - **Personalised / individualised**
 - **Signposting to resources**
- **Striking need for multiple ways of learning**



HOW?

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



Accessible in four ways:

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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

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

Advantage: Enable content fidelity & ease maintenance (updatable)

Learning about Breathlessness 2



Aim of LaB2:

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

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Coming into LaB2...

1) Understanding breathlessness



2) Anxiety, panic and breathlessness



3) Managing infections



4) Keeping active



5) Living positively



6) What to expect in the future



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

Bereaved carers – data collection

Topic-guided focus groups

Co-facilitated:
two researchers
+ former carer

Support person present

Topic-guided interviews

One researcher

Audio recorded & transcribed

Analysed using Framework

Follow up calls + cards + support contact available

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 patient's condition worsened

- 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

Coping with symptom changes as the illness worsened

“It would have been nice to have that explained to us...why this is happening” – 01-016, COPD

2) Discussing “the future” with others

- Wider social issue, of people generally being unable to discuss death – making their grieving even more difficult
 - *“We don’t talk about it as a society, it’s a taboo subject [...] I can understand it’s very hard but there should be some encouragement to talk about it”*

[01-008, Cancer]

Discussing the ‘future’ with others

“In hindsight, I wish I’d have known it was coming because we had no preparations, we didn’t talk about death, she was too young” – 04-010, Cancer

3) Accessing care and support

- All carers felt dissatisfied with aspects of care:
 - e.g. excluded from patient treatment decisions, unavailability out of hours, poor continuity of care from hospital to home, lack of direct explanations to carers e.g. prognosis, meaning of “palliative” etc.
- Almost all mentioned aspects they were happy with:
 - Quite tearful about high quality of care

Accessing care and support

“What I found really difficult was being kept out of it even though I was his power of attorney and I was his next of kin...” – 05-010, COPD

4) Administrative tasks

- Unprepared for the amount of practical, administrative jobs that needed to be done once their patient had died
 - *“It takes a long time to get things sorted afterwards”*
[03-010, Cancer]
- Helpful to have arrangements organised together with the patient, in advance:
 - *“We’d sorted it out and she’d talked to the funeral directors, got the plan of everything, there was very little I needed to do”*
[01-008, Cancer]

Administrative tasks (e.g. registering the death)

“Maybe encouraging people to have a word with solicitors, legal advisors [...] make very sure there’s as clear a will as possible” – 03-010, Cancer

5) Coping with emotions after the patient's death

- Struggled with range of difficult emotions after the death:
 - Shock
 - Guilt
 - Sadness
 - Anger
- *“A little bit of guilt because at times I was hard on my mum because I didn’t fully understand what she was going through”* [01-017, COPD]
- *“I’m furious...I’m angry that...it could take a 58 year old wife who’d got everything to live for”* [04-010, Cancer]

Coping with emotions after patient death

“Even though you’re expecting it [...] there’s a shock you mustn’t underestimate” – 01-008, Cancer

Viewing the topic with the patient

- ...it is *up to the individual*. I think they will make it clear if they want to talk about these things because if they don't it might play on their mind and make them upset

[03-006 COPD]

- Hearing about someone else's experiences, that *might have opened her up to talk to me more* openly about it or... for me to broach the subject

[01-017 COPD]

- ...she would be thinking *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)



Review with Carer Advisory Group (PPI)



Review with Study Advisory Group



Current carers: March 2019 (workshops)

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**





Welcome to 'Supporting someone with breathlessness'

'Supporting Someone with Breathlessness' is a source full of help and advice made for family and friends of people with breathlessness (sometimes called "carers").

To make sure it is as helpful to you 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.



[Caring for someone with Cancer? Click here](#)

[Caring for someone with COPD? Click here](#)

Support topics

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

Supporting Someone with Breathlessness

Clinical experts



Supporting Someone with Breathlessness



Roberta Lovick
Experienced Carer

Peer carers



Sophie Howson
Doctor, Nurse and Former Community Matron

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

- **Bereaved carers were able to express what they would have liked to have known regarding “what to expect in the future”**
- **Enabled creation of sensitive website content mapped to their learning needs**
- **LaB2 is thus developing a resource with relevant and appropriate content for carers of people with breathlessness in advanced disease**

LaB Programme – Funder Acknowledgements

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Photo credits

https://www.youtube.com/watch?v=pa_HXrwoAfw&feature=youtu.be



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



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Thank you



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