

## **The journey to diagnosis and treatment among people with bronchiectasis**

Bronchiectasis is a chronic lung disease that, after many years, is receiving growing recognition and consideration. While there are recent guidelines about diagnosis and treatment, over past decades many patients with bronchiectasis have not been properly diagnosed and treated.

The airways are hollow tubes that allow us to breathe in air and cough out sputum (phlegm). People with bronchiectasis have scarring of these tubes which makes it difficult to clear sputum . If not properly cleared, sputum accumulates, and the airways can become infected with bacteria which may lead to repeated chest infections and a poor quality of life.

One of the most important treatments of bronchiectasis is regular airway clearance, sometimes referred to as chest physiotherapy. This includes anything you do by physical means to help loosen and clear phlegm from your chest. There are many methods of chest clearance and none has been proved to be superior than others. Although very important, there are challenges to successful and regular performance of airway clearance.

This survey is intended for people with bronchiectasis and their relatives. First, we want to learn about the difficulties people may have had until they received a diagnosis and appropriate treatments for bronchiectasis. Second, we want to learn about successes and challenges that people with bronchiectasis may experience in performing regular chest clearance.

This survey will take up to 20 minutes to complete, and is anonymous. You may ask other people – your relatives, nurse, physiotherapist, or doctor - to help you with answers you are not sure of but we want to hear about your experiences. If you would like to receive updates or would like to become more involved in the project, please enter your email address at the end of the survey.

### Part 1: General information

- 1) **You are...?**
  - a. A person with bronchiectasis
  - b. A parent, relative or carer of someone with bronchiectasis
  - c. Other
- 2) In which country do you live?
- 3) What is your age (years)

### Part 2: The journey to diagnosis

- 4) How long did you have symptoms before bronchiectasis was diagnosed?
  - a. Less than 1 year
  - b. Between 1-2 years
  - c. Between 2-5 years
  - d. Between 5-10 years
  - e. Longer than 10 years

- f. Since childhood
  - g. Other/ do not remember
- 5) Did you receive any other diagnoses (such as asthma, COPD) to explain your symptoms before bronchiectasis was diagnosed? If yes, what were they?
- a. No- the first diagnosis was bronchiectasis (please proceed to Q #8)
  - b. Yes- I was diagnosed with a different disease before being diagnosed with bronchiectasis , but the correct diagnosis is bronchiectasis.
  - c. Yes- I was diagnosed with a different disease, I actually have both diseases .
- 6) For patients who answered “yes” to question #5 (received a different diagnosis before being diagnosed with bronchiectasis) what was your first diagnosis?
- a. Asthma
  - b. COPD
  - c. Chronic bronchitis
  - d. Chronic lung infection
  - e. Chronic sinusitis or rhinitis
  - f. Acid stomach problems (reflux, gastric ulcer)
  - g. Another, please specify
- 7) For patients who answered “yes” to question #5 (received a different diagnosis before being diagnosed with bronchiectasis) did you receive any treatments before your diagnosis of bronchiectasis that were unhelpful?
- a. Inhalers
  - b. Nebulisers
  - c. Antibiotics
  - d. Other, please specify (free text)
- 8) The following questions relate to tests you had to diagnose the cause or severity of bronchiectasis. **For each** please state “Yes/No/Not sure”
- a. Sputum (phlegm) samples for bacteria.
  - b. Sputum cultures when you have an exacerbation.
  - c. Blood tests to measure the strength of your immune system.
  - d. Tests for cystic fibrosis: sweat test, genetic testing
  - e. Tests for Primary Ciliary Dyskinesia (PCD): nasal brush for electron microscopy or video microscopy, genetics, nasal NO (Nitric oxide).
  - f. Blood or skin tests for allergies.
  - g. Spirometry assessment of lung function (breathing tests that measure the amount of air that goes in and out of your lung when you breathe forcefully).
- 9) Which of the following is most accurate regarding your bronchiectasis care:
- a) My general practitioner is my primary care provider
  - b) My doctor is a respiratory specialist but does not specialise in bronchiectasis
  - c) My doctor runs a bronchiectasis clinic but the centre does not specialise in bronchiectasis
  - d) My hospital is a referral centre for bronchiectasis
  - e) Other (please specify)
- 10) Have you experienced any challenges with the treatment of chest infections? For each statement please state whether this is/was "Not an issue, Not very difficult, Difficult, Very difficult, No opinion"

- a. Having access to a primary care doctor (family doctor, general practitioner) that has a good knowledge about treatment of chest infections in someone with bronchiectasis
- b. Getting sputum cultures performed when infection starts
- c. Delays receiving the results of sputum cultures
- d. Other? (please specify)

Part 3: Airway clearance (“physiotherapy”)

- 11) Do you cough up phlegm/sputum?
- a. Yes- more than a cupful a day
  - b. Yes- between half a cup and a cup per day
  - c. Yes- a small amount each day
  - d. Yes- but not every day
  - e. Yes- only when I have a chest infection
  - f. No- I don’t cough up phlegm
- 12) Has your doctor recommended you practice regular physiotherapy to clear your airways/chest? Yes/ no
- 13) Were you referred to a specialist (usually a physiotherapist) to learn how to perform chest clearance? yes/no (if you answered “no”, please go to #17)
- 14) If you answered “yes” to question 13, how long after you were first diagnosed did you see a physiotherapist?
- a. Immediately
  - b. Less than 1 month
  - c. Between 1 and 6 months
  - d. Between 6 months - 1 year
  - e. Between 1 - 2 years
  - f. Between 2 - 3 years
  - g. Between 3 - 5 years
  - h. Longer than 5 years
- 15) If you answered “yes” to question 13, when were you trained in taught to practice chest clearance exercises?
- a. I was trained during a chest infection
  - b. I was trained when well
- 16) Where did you first receive the chest clearance sessions?
- a. In a hospital
  - b. In a primary care clinic
  - c. In a specialty clinic / a private practice
  - d. At home (by a physiotherapist)
  - e. Other, please specify (free text)
- 17) If you answered “yes” to question 13, how many times have you met with this specialist while learning chest clearance?
- a. Once
  - b. Between 2-5 times
  - c. Between 6-10 times
  - d. More than 10 times

e. Do not remember/ don't know

18) Were you directed to any internet resources (such as videos) to teach you about chest clearance techniques? Yes/no

19) If you answered "yes" to **question 13 or 18**, who told you about this resource?

- a) Primary care team (general practitioner or practice nurse)
- b) A respiratory doctor ~~physician~~
- c) A rehabilitation doctor ~~physician~~
- d) A physiotherapist
- e) Another health care professional
- f) A website
- g) I got referred to a physiotherapist independently

20) If you answered "yes" to **question 13 or question 18**, which chest airway clearance techniques were you shown? Please **select all that apply**:

- a) Postural drainage <sup>1</sup>
- b) Chest clapping (percussions) / vibrations / shaking<sup>2</sup>
- c) Active cycle of breathing techniques (ACBT) <sup>3</sup>
- d) Autogenic drainage (AD)<sup>4</sup>
- e) Slow expiration with glottis opened in lateral posture (ELTGOL)<sup>5</sup>
- f) Cough manoeuvres or forced expiratory technique (FET) / huff<sup>6</sup>
- g) Regular physical activity / exercise
- h) Respiratory muscle training
- i) Unknown/ not sure what the technique is called
- j) I wasn't instructed in any of these techniques

21) Which of the above techniques do you use regularly? Please select **all that apply**

- a. Postural drainage<sup>1</sup>
- b. Chest clapping (percussions) / vibrations / shaking<sup>2</sup>
- c. Active cycle of breathing techniques (ACBT) (deep forceful breaths followed by open-throated shallower breaths followed by huffing) <sup>3</sup>
- d. Autogenic drainage (AD) <sup>4</sup>
- e. Slow expiration with glottis opened in lateral posture (ELTGOL) <sup>5</sup>
- f. Cough manoeuvres or forced expiratory technique (FET) / huff<sup>6</sup>
- g. Regular physical activity / exercise<sup>7</sup>
- h. Respiratory muscles training
- i. Unknown/ not sure how the technique is called
- j. I don't use any of these techniques

**22)** Do you have access to or own one or more of the following devices? **Please select all that apply**:

- a. **Oscillatory positive expiratory pressure devices (O-PEP)<sup>8</sup>:**
  - i. Acapella
  - ii. Flutter
  - iii. Cornet
  - iv. Aerobika

- v. Bubble PEP
- b. Fixed positive expiratory pressure devices (PEP)<sup>9</sup>:
  - i. PEP-Mask
  - ii. PEP-Valve
  - iii. TheraPEP
- c. Instrumental chest vibration (vest) <sup>10</sup>
- d. Other (please specify)
- e. I have a device but don't know its name
- f. None

23) What device do you use regularly in your airway clearance routine? Please select all that apply Oscillatory positive expiratory pressure devices (O-PEP) <sup>8</sup>:

- i. Acapella
- ii. Flutter
- iii. Cornet
- iv. Aerobika
- v. Bubble PEP
- g. Fixed positive expiratory pressure devices (PEP) <sup>9</sup>:
  - iv. PEP-Mask
  - v. PEP-Valve
  - vi. TheraPEP
- h. Instrumental chest vibration (vest) <sup>10</sup>
- i. Other (please specify)
- j. I have a device but don't know its name
- k. None

23) **Do you do regular chest clearance exercises when you are well, and how often?**

- a) Yes, more than twice a day
- b) Yes, twice a day
- c) Yes, once a day
- d) Yes, between 3 times per week to once a day
- e) Yes, less than 3 times per week
- f) Yes, but only when I have a chest infection **(go to question 25)**
- g) No, I do not do exercises to clear my chest **(go to question 25)**

24) Do you increase the frequency or duration of your chest clearance exercises during a chest infection?

- a) Yes, I increase the frequency
- b) Yes, I increase the duration
- c) Yes, I increase the frequency and duration
- d) No, I usually do the same
- e) No, I am too tired to do the exercises during a chest infection

25) In your opinion, what is a good way to tell if your airway clearance technique is effective? Please check all that apply

- a) I bring up more sputum while or after performing the airway clearance exercises
- b) I bring up less sputum while or after performing the airway clearance exercises
- c) I bring up less sputum during the day

- d) I cough less during the day
- e) I am more energetic during the day
- f) I get sick less often
- g) Other (please specify)
- h) I don't know/ can't tell

27). In your opinion, which, if any, of the following obstacles prevent people with bronchiectasis from performing chest clearance regularly? Please select one or more of the following:

- a. Not being referred to a doctor or nurse
- b. Lack of access to a physiotherapist
- c. Cost of devices
- d. Chest clearance takes too much time
- e. Doing chest clearance is boring
- f. Chest clearance is not effective
- h. Lack of energy to perform chest clearance
- i. Other, please specify
- h. There are no obstacles to chest physiotherapy

28) Have you attended a formal program of pulmonary rehabilitation? Yes/no  
(Pulmonary rehabilitation is a course lasting at least 6 weeks and involving supervised exercise and education sessions)

29) If you answered "yes" to **question 28**, for how long did you attend the rehabilitation program? \_\_\_\_\_ (3 months or less/between 3 and 6 months/longer than six months)

30) If you have not attended a formal program of pulmonary rehabilitation, what was the reason?

- a. I have never been offered the chance to attend
- a. There is no program available where I live
- b. There is a program but I was told I was not eligible
- c. I was offered the chance to attend but didn't feel able to
- d. The program was too difficult to get to
- e. I am too busy to attend the programme
- f. Other, please specify