

## Online Supplement

### Giving Voice to People – Experiences During Mild to Moderate Acute Exacerbations of COPD

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##### **Dealing with AECOPD**

*(not) depending on others*

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##### **Main needs during AECOPD**

*Breathe better*

*Feel less tired*

*Get rid of sputum*

*Be able to walk*

##### **(Un)certainty about PR**

*Lack of knowledge*

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*Design and timing*

*Trust in health professionals*

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### **Impact of AECOPD**

#### **Symptoms**

##### Perceived symptoms

"So, I walk, yes, I know what I do and what I say, but I don't have strength, I suffer a lot with lack of energy." (Mary, 67)

"It is very difficult to breathe." (Mary, 67)

"I don't have strength and energy." (Mary, 67)

"It is hard to breathe..." (Mary, 67)

"It is the tiredness, the tiredness. The breathing, the shortness of breath." (John, 75)

"Now I have more sputum and it gets stuck if I don't take the medicine." (John, 75)

"I feel really tired in the morning, I barely get up. As soon as I put my feet on the ground, I start dressing and I'm already tired." (Peter, 64)

"Now I have cough and sputum." (Peter, 64)

"My chest feels very tight. It seems that I have to make a huge effort to be able to breathe. I'm making a lot of effort, I'm really making a really big effort to be able to breathe." (Peter, 64)

"I also have some wheezing in the morning." (Peter, 64)

"The shortness of breath. A bit of lack of energy also. Because usually, when I have acute exacerbations, I have shortness of breath and I also get way more tired than the usual." (James, 78)

"I have sputum and cough to go along with it." (James, 78)

"I feel tired." (James, 78)

"Sometimes I have cough. I've already been in the doctor because of it." (Oliver, 63)

"I feel that my chest is heavy and wheezing also." (Oliver, 63)

"The shortness of breath, the shortness of breath, it is what I notice, my biggest difficulty. It is the shortness of breath." (Harry, 87)

"I take a deep breath but there is something that holds it, it seems that it is stuck inside." (Harry, 87)

"I get exhausted, the difficulty is to breathe and physical. I get exhausted, what I call exhaustion." (Rose, 62)

"It was the pain. It was the pain, the shortness of breath also, but mainly the pain." (Ethan, 58)

"I feel that I have sandpaper or a claw here in the bronchial area that scratches when I breath, it seems like the air is carrying sand together. And pain, and itchy throat and a bit of cough, but a dry cough. Now taking the medicine the sputum is already coming out, little by little, a little greenish." (Ethan, 58)

"When I talk for a bit, I start coughing like I am doing now." (Ethan, 58)

"When I breathe it feels like sandpaper inside." (Ethan, 58)

"Mainly sputum is something that makes me very distressed. It bothers me a lot. And the more I cough, the more difficult it becomes to get out. But when it gets out it is like a fried egg. The sputum is much more quantity and thicker too." (Thomas, 56)

"When I start to cough a lot, I feel very tired." (Thomas, 56)

"The wheezing is the number one. It seems like a grill frying chips." (Thomas, 56)

"The sputum is what has really created more problems for me, because it is true that afterwards I become more desperate." (David, 72)

"Sometimes I avoid to expectorate because I know that afterwards I will get even more tired." (David, 72)

"As at night I have more cough and sputum, then it is more difficult to fall asleep. But if I don't expectorate then I can't sleep." (David, 72)

"After expectorating several times, if I expectorate everything I can, then I'm able to sleep... I don't say for hours and hours, but for some good two to three hours." (David, 72)

"If I don't have the need to expectorate, then I'm completely well without a problem. When I do have the need to expectorate, then it is when it comes the so-called seizure and everything comes." (David, 72)

"I feel short of breath." (Michael, 58)

"It is the short of breath and the tiredness." (Michael, 58)

#### Onset and daily variability

"The weather also has a lot of influence." (John, 75)

"I feel really tired in the morning, I barely get up. As soon as I put my feet on the ground, I start dressing and I'm already tired." (Peter, 64)

"I also have a bit of wheezing in the morning, at least as soon as I wake up and at night I start wheezing. It is in the morning and at night. During the day I don't have barely anything. At night and in the morning I have more wheezing and also more sputum. And when I have more wheezing then I also become much more tired." (Peter, 64)

"During the day the tiredness becomes better. Around 6 or 7 pm it is when it starts to get worse again." (Peter, 64)

"Sometimes it's a bit difficult to get the sputum out, other times it comes out better." (Peter, 64)

"The sputum and cough occur more at night." (James, 78)

"At night usually I am not tired nor short of breath. Neither in the morning. Usually walking, doing things and walking it is when I start to feel tired." (James, 78)

"The steam, the humidity of the hot air. Too much sun also. And when there is a lot of rain, I find myself desperate." (Ethan, 58)

"When I talk for a while, I cough just like I am doing now." (Ethan, 58)

"It is difficult to breath mainly when I am making efforts." (Thomas, 56)

"When I am making a little bit of effort, it is when I feel I start wheezing more. Besides that, when I am sitting or lying, if I am straight like this I feel a lot of wheezing, if I raised the headboard then I feel less wheezing." (Thomas, 56)

"I have moments that I feel more relieved [regarding cough and sputum]. And I have other moments that are worst, mainly at night when I go to bed, maybe because of the heat of the bed, I don't know, I feel more affected. In the morning when I get up I also feel it a bit, but then during the day it gets better." (David, 72)

#### Relation between symptoms

"It is the general tiredness. And then I get very distressed, I get this tightness." (Peter, 64)

"When the wheezing starts, I become much more tired." (Peter, 64)

"When the wheezing starts, I hear this cricket here, and I already know that I am much more tired." (Peter, 64)

"The problem is that the sputum might be also contributing to this tiredness." (Peter, 64)

"I believe that by relieving the sputum then it would also improve the cough." (Peter, 64)

"Because usually when I have acute exacerbations, I have shortness of breath and I also get way more tired than the usual." (James, 78)

"And then when something doesn't go well, I get nervous, and it is worst. Then, it is even worse." (James, 78)

"Because if I was able to breath better the tiredness wouldn't be so much. I believe it wouldn't." (James, 78)

"If I have to hurry up I immediately become distressed. And if I get a bit nervous then it is even worse." (Harry, 87)

"Shortness of breath and tiredness. Both things. One is not without the other." (Rose, 62)

"I become anxious. And I find it more difficult to breath because I am anxious." (Rose, 62)

"The tiredness and shortness of breath, they are connected." (Ethan, 58)

"And the more I cough, the more difficult it becomes to get the sputum out." (Thomas, 56)

"When I cough, when I start coughing a lot I feel really tired." (Thomas, 56)

"Sometimes I avoid to expectorate because I know that afterwards I will get even more tired." (David, 72)

"The cough, you know, one thing is connected with the other, the cough pulls the sputum and sometimes the sputum is a little more difficult and pulls the cough." (David, 72)

"As at night I have more cough and sputum, then it is more difficult to fall asleep. But if I don't expectorate then I can't sleep." (David, 72)

"After expectorating several times, if I expectorate everything I can, then I'm able to sleep..." (David, 72)

"If I don't have sputum then I also don't have the need to cough." (David, 72)

### **Physiological changes**

"I feel that I'm lacking oxygen. And then my brain starts working, and there is something missing when I want to walk, when I want to breath and I can't, and I feel that I lack something to be able to put inside what I may not be able to get normally, to cheer me up." (Mary, 67)

"As I get older, I feel that the respiratory crises are getting worst, heavier, stronger. I feel increasingly less knowledgeable. I'm loosing my abilities, both mental and physical." (Mary, 67)

"The air, the peripheral oxygen saturation doesn't decrease much." (Peter, 64)

"My problem is breathing and also physical." (Rose, 62)

"It is like if there was no oxygen in my muscles and then I feel my legs really heavy." (Ethan, 58)

### **Limitations in activities of daily living**

"I want to do something and I can't. I am going to do it and I have to stop." (Mary, 67)

"I have to stop. What I used to do in one or two minutes now it may take me almost half an hour." (Mary, 67)

"There are things that I have to do more slowly." (John, 75)

"It changes everything because I feel very dizzy." (Peter, 64)

"Before I used to do almost everything, I used to do everything more or less as everyone. Now I can't." (Peter, 64)

"Before I wasn't able to do everything but I was able to do much more than now." (James, 78)

"Anything that I have to do at home, I have to do it slower than before." (James, 78)

"It affects my ability to walk. When I want to do something, I can't." (Harry, 87)

"I can't. I want to do something and I become stuck, I feel there is something arrest inside, I don't know." (Harry, 87)

"It affects my quality of life because I am a very active person." (Rose, 62)

"For me it is a bit bad because it doesn't let me do what I want." (Thomas, 56)

"The impact is negative, without a doubt." (David, 72)

"Sometimes I have to stop what I am doing to expectorate, I have to go to the bathroom or to the garbage dump." (David, 72)

#### Basic activities of daily living

"It is very hard to breathe, I can't climb the stairs." (Mary, 67)

"Even to go to the bathroom is hard for me at the moment. So, I make a really big effort to be able to do it." (Mary, 67)

"As soon as I put my feet on the ground, I start dressing and I'm already tired. Even getting dressed. Taking a shower is another problem. A few days ago, I tried to take a shower when there was no one at home... I am not able to do it anymore, only when my wife or my daughter are at home, because I am scared of taking a shower alone. I was taking a bathtub and found myself really in distress." (Peter, 64)

"I have to take a shower really slowly." (Peter, 64)

"Going down the stairs in the building there is no problem, my problem is to climb the stairs, because I know that when I go down then I have to climb them. Sometimes I stay downstairs waiting for my wife to arrive so that I can come up with her." (Peter, 64)

"It makes it difficult to walk." (Harry, 87)

"I need to walk the usual, what I feel it is the usual, and the acute exacerbation makes it difficult." (Rose, 62)

"It makes it difficult to, for example, I put on some shoes and I am already tired. Walking a bit, after 10, 15, 20 meters I have to stop or at least slow down." (Ethan, 58)

"I feel that I am not able to walk like other people." (Michael, 58)

#### Instrumental activities of daily living

"I can't do my regular activities, not even making the bed. Something as simple as making the bed at this moment I can't." (Mary, 67)

"I can't even leave the house to catch the bus." (Mary, 67)

"While climbing stairs I can't carry anything with me. Before I was able to carry some groceries, now I cannot carry anything at all." (Peter, 64)

"I feel short of breath while talking." (Ethan, 58)

"I would like to be able to carry some weights, and also to go grocery shopping and come back carrying the bags, but I cannot do it anymore because it is difficult." (Thomas, 56)

#### Advanced activities of daily living

"Now I can't go fishing. I used to entertain myself by going fishing and I spent the time better, but now I can't." (Peter, 64)

"I had to unscheduled all my work, from morning to night, it was the day I work the most and I had to unscheduled everything. Also because I was going to be sabotaging my work, I wouldn't be able to do it properly. It also reduces my productivity and affects my self-sufficiency." (Ethan, 58)

"There is one thing that I've noticed that it is difficult for me to sing." (Ethan, 58)

"Sometimes I can't go with my friends here and there. I can no longer keep up with them." (Michael, 58)

"I want to have fun, to be able to go to everything, and I can't go..." (Michael, 58)

### **Social constrains**

"It affects my self-sufficiency. And isolation, of course, isolation." (Ethan, 58)

"I don't want to expectorate in front of others, it is not pleasant. Neither for me, even less for the others." (Ethan, 58)

"If I need to expectorate, I am careful to expectorate to a proper local like a tissue." (David, 72)

"Sometimes I can't go with my friends here and there. I can no longer keep up with them." (Michael, 58)

"I want to have fun, to be able to go to everything, and I can't go..." (Michael, 58)

"I could go somewhere but if I have cough I don't go inside, I don't go there. Sometimes because of other people." (Michael, 58)

### **Psychological and emotional challenges**

"I feel really down. And then I get nervous because I want to do something, and I can't. I am going to do it and I have to stop." (Mary, 67)

"So I make a really big effort to be able to do it." (Mary, 67)

"I was always a very active woman but with these respiratory crises I am getting worse and worse. I feel I am going down." (Mary, 67)

"I don't even want to go outside anymore. I just don't want to. I no longer want to do anything; I don't feel like leaving the house anymore." (Peter, 64)

"A few days ago, I tried to have a shower when there was no one at home... I am not able to do it anymore, only when my wife or my daughter are at home, because I am scared of taking a shower alone. I am scared of getting short of breath and then there is no one there to help me." (Peter, 64)

"A few days ago I was having a bathtub and I had to go to the living room in distress with a feeling like... maybe it was panic, I don't know. I get anxious. I was having a bathtub and found myself in distress, probably it was fear, I don't know." (Peter, 64)

"In the morning I walk around inside the house, from side to side, I feel like a prisoner, everything upsets me already." (Peter, 64)

"Now I don't even try to go fishing because I already think that something will go wrong, so I don't even go, I don't even pick the fishing rod." (Peter, 64)

"I feel little desire to do certain things." (James, 78)

"When something doesn't go well, I get nervous and then it is even worse." (James, 78)

"It is hard for me to cope with the difficulty to breath. I mean, I don't know how to handle it." (Rose, 62)

"I become anxious. And I find it more difficult to breath because I am anxious." (Rose, 62)

"There is a feeling of frailty and disability." (Ethan, 58)

"And it was the state that I became due to pain, it sent me really down and I got discouraged." (Ethan, 58)

"I don't feel like going out, and then inwardly I want to unscheduled things. And isolation, of course, isolation." (Ethan, 58)

"Besides being bothering others, it also bothers me because I feel I had no need to do it but I have to, I have to expectorate." (David, 72)

"Sometimes I get angry because I want to do something and I can't... I feel frustrated." (David, 72)

"I could go somewhere but if I have cough I don't go inside, I don't go there. Sometimes because of other people." (Michael, 58)

### **Family disturbances**

"The sputum makes me feel desperate and then I bother my family, I know it." (David, 72)

"Besides being bothering others, it also bothers me because..." (David, 72)

"I get a bit angry because I want to do something and I can't, and then maybe I create a bit of a bad environment at home." (David, 72)



## **Dealing with AECOPD**

### **(not) depending on others**

"A few days ago, I tried to have a shower when there was no one at home... I am not able to do it anymore, only when my wife or my daughter are at home, because I am scared of taking a shower alone." (Peter, 64)

"Going down the stairs in the building there is no problem, my problem is to climb the stairs, because I know that when I go down then I have to climb them. Sometimes I stay downstairs waiting for my wife to arrive so that I can come up with her." (Peter, 64)

"I shower alone. Sometimes my wife is at home, others she is not, because she has her own things to do, and often I only shower when she is back. Usually I shower alone, but I always calculate more or less how I am feeling so I don't have any problems." (James, 78)

### **Planning and compensation strategies**

"It is very hard to breathe, I can't climb the stairs, I have to climb them step by step. One step stop, another one stop, always like this, for someone who lives in the third floor." (Mary, 67)

"And what helps me is the car, because if it wasn't the car..." (Mary, 67)

"I have to stop. What I used to do in one or two minutes now it may take me almost half an hour." (Mary, 67)

"The way I feel better is lying down, barely moving." (Mary, 67)

"There are things that I have to do more slowly." (John, 75)

"I have to take a shower really slowly." (Peter, 64)

"I leave the house but I can only do it around 10:30 or 11am. Before I would left the house immediately, at 9am or even earlier." (Peter, 64)

"I have to climb the stairs slowly and split them in three or four parts. And I can't carry anything with me." (Peter, 64)

"I'm making a lot of effort, I'm really making a really big effort to be able to breath. But if I use the oxygen, it is the same. I don't feel differences, I'm still making an effort, making a really big effort to be able to breath." (Peter, 64)

"Anything that I have to do at home, I have to do it slower than before." (James, 78)

"I shower alone. Sometimes my wife is at home, others she is not, because she has her own things to do, and often I only shower when she is back. Usually I shower alone, but I always calculate more or less how I am feeling so I don't have any problems." (James, 78)

"I reduce my daily activities. I also have to do them slower, but I reduce them. And I recover, and then I do another one." (Rose, 62)

"Sometimes I think to myself, yoga breathing, with your belly, and it helps." (Rose, 62)

"Walking a bit, after 10, 15, 20 meters I have to stop or at least slow down." (Ethan, 58)

"When I talk for a bit, I start coughing like I am doing now. It means that now I'll have to remain silent for a while to rest." (Ethan, 58)

## **Main needs during AECOPD**

### **Breathe better**

"I need to improve my respiration." (Mary, 67)

"What I feel I need is the air. Because if I have air it gives me (at least I think) more agility, which is what I am lacking at this moment." (Mary, 67)

"I need to breathe better and to feel less tired." (John, 75)

"I need to breathe better. Because if I breathed better the tiredness wouldn't be so much. At least I suppose it wouldn't." (James, 78)

"I just wanted to get my chest better. The breathing. It is important, very important to me." (Oliver, 63)

"I need to breath better and to feel less tired." (Oliver, 63)

"I would like to improve this part of getting air inside... the air, the air." (Harry, 87)

"I would like to improve my respiration. To open my chest... sometimes I feel it is heavy, tight, I don't know how to explain it." (Rose, 62)

"I need to feel less tired and to breathe better, they are connected." (Ethan, 58)

"I need to have more ability to breath." (Ethan, 58)

"I need the breathing to get back to normal. Normal is difficult, but at least improve the respiratory part. Especially when I'm making efforts. That's when I would like you to help me more, so I can be more comfortable." (Thomas, 56)

### **Feel less tired**

"I need to breathe better and to feel less tired." (John, 75)

"I need to feel less tired. My problem is really the general tiredness." (Peter, 64)

"Heck, if I wasn't always tired I would get better, feel better." (Peter, 64)

"I need to feel less tired." (Peter, 64)

"I need to breathe better and to feel less tired." (Oliver, 63)

"I need to feel less tired and to breathe better, they are connected." (Ethan, 58)

### **Get rid of sputum**

"I believe it is important to relief the sputum." (James, 78)

"My main need is the sputum, to get rid of this sputum. It is something that bothers me. If I don't have sputum then I also don't have the need to cough." (David, 72)

"When I do have the need to expectorate, then it is when it comes the so-called seizure and everything comes. That is my main problem." (David, 72)

### **Be able to walk**

"Hmm... I would like to be able to walk like I used to walk. I would get up at 5 or 6 am and just go." (Michael, 58)

"I want to be able to walk." (Michael, 58)

"I want to be able to walk, to be able to walk at my own will." (Michael, 58)

## **(Un)certainty about PR**

### **Lack of knowledge**

"I have no idea, one session at a time." (Mary, 67)

"I don't know, I haven't seen it yet." (John, 75)

"Oh that I don't know, only at the end I will be able to tell you." (Harry, 87)

"First I had to be aware of the plan that you have, to know what favours me." (Ethan, 58)

"Only the health professionals will be able to know." (Thomas, 56)

### **Get better**

"I think, well I want to get better." (John, 75)

"My idea is to get better." (John, 75)

"I think I will get better. Possibly in everything, but at least the tiredness." (Peter, 64)

"I think I will get better, yes, yes, yes. It will get better." (James, 78)

"I think it will be positive. Yes, I think I will get a bit better. My expectations are always for everything to happen better. To always get better, may it be better for me." (Thomas, 56)

"My expectations are always to get better." (Thomas, 56)

### **Exercises**

"I think the exercises could make me get even worse." (Mary, 67)

"Hmm, the breathing exercises in this critical phase help me even less." (Mary, 67)

"The physical exercises improve, improve... If it doesn't improve it also doesn't get worse." (John, 75)

"For example the exercise with the chair, I like to do it. I get tired immediately. It helps, it helps." (Oliver, 63)

"I like to do the exercises at home. Later I am already going to do this exercise by myself." (Oliver, 63)

"I think that, in the situation that I am in, due to the muscle mass or to what my body already asks for, the weakness, the oxygen, walking can help. I feel the walk training helps." (Ethan, 58)

"I am sure. To exercise is fundamental. Because... the muscles ask for more." (Ethan, 58)

## **Design and timing**

"There are different exercises, some more intense, others less intense." (John, 75)

"You learn a little of everything." (John, 75)

"It would be important to learn how to breath." (John, 75)

"Anything that involves a lot of effort I can't, at this moment I can't do big efforts. Less intense exercises, without weights, or as long as it is not too heavy and it is not for too long, I don't know. Less exercise time and lighter weights." (Peter, 64)

"The breathing techniques would help." (Peter, 64)

"I think it can be similar to the stability pulmonary rehabilitation programme." (James, 78)

"I do the same exercises, even if they feel a bit more difficult." (James, 78)

"I think I should wait two or three days. (...) In two or three days my breathing might be better, I believe." (James, 78)

"The breathing techniques would help." (James, 78)

"I think the education and psychosocial support sessions could be about the same themes, from my point of view I think it is everything normal." (James, 78)

"It would be important to learn how to manage symptoms." (Oliver, 63)

"Hmm... Rehabilitation could be with exercises that I could learn that would open my chest and help me breathe better. Maybe there is a way I could breathe better, no?" (Rose, 62)

"First I have to be aware of the plan that you have, to know what favours me, and then understand what fits me, in my individual case." (Ethan, 58)

## **Trust in health professionals**

"But you do everything (...) I know that you do everything to make me get better." (John, 75)

"Only the health professionals will be able to know." (Thomas, 56)

"I trust in people. Especially in the health professionals." (Thomas, 56)