

# Exacerbations: how people with COPD and their doctors view and talk about flare-ups

As a community of people living with and caring for those with COPD, we listen and learn from each other. One of the most important conversations we have is around exacerbations, or flare-ups where COPD symptoms become worse than usual. We know these stressful and harmful episodes can be prevented and that it is very important to prevent them. We also know there is confusion about what an exacerbation is and what can be done to avoid one.

Being able to speak openly and clearly with a health care professional (HCP) like your doctor, nurse or respiratory therapist is key to helping you learn more about COPD flare-ups so that you will notice them earlier. This can help you to better manage symptoms of the exacerbation and help prevent the next one.


To find better ways to support everyone being able to talk more clearly and more often about COPD exacerbations, the COPD Foundation has partnered with the American College of Chest Physicians (CHEST) and AstraZeneca (AZ) to ask people with COPD and doctors who care for people with COPD how they talk with each other about COPD exacerbations. Together with your help, we completed two surveys about COPD exacerbations and want to share the results.

*The goal of this work is to find better ways to talk about and understand COPD exacerbations, whether you are living with COPD or caring for someone who does. We think that by helping physicians and families talk to each other, we can improve lives by better recognizing, treating and preventing COPD exacerbations.*

## Key Takeaways and Opportunities

Key results from our two 2020 surveys completed by 428 people with COPD and 401 physicians who care for people with COPD show that both groups highlight many opportunities to better address COPD exacerbations.

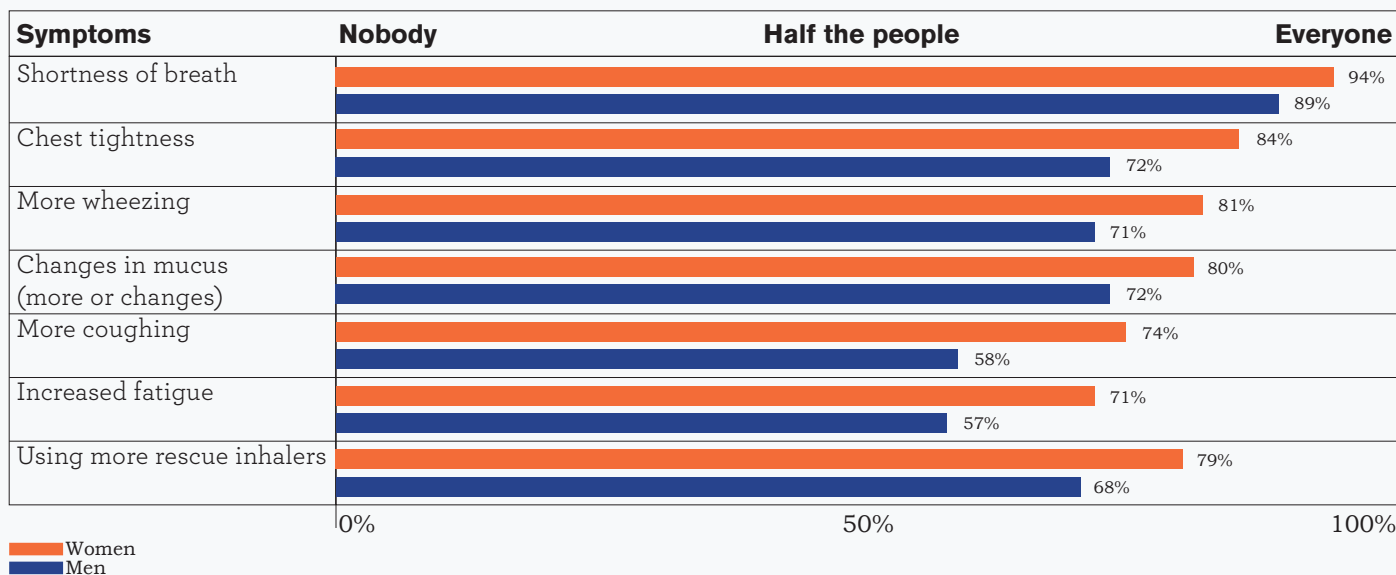
### Most people with COPD who answered the survey said they have had an exacerbation.

- More than 8 of every 10 (83%)  people with COPD who answered our survey told us they had one or more exacerbations in their lifetime and knowing how to prevent COPD flare-ups helped them have fewer exacerbations.
- Women reported more symptoms than men that they used to recognize exacerbations. (Figure 1)

### How do people with COPD see exacerbations?

- People who completed the survey said that shortness of breath, chest tightness, more/new wheezing, coughing, fatigue and increased use of rescue inhalers were signs and symptoms when they had a flare-up. (Figure 1)

**Figure 1. What are symptoms of a COPD exacerbation? Patient report**



- Almost half or 1 in 2 (46%) 🧑🧑 people of people with COPD who answered this survey said they do not know how to prevent exacerbations or flare-ups.

**Though it is important to take care of exacerbation symptoms early, we learned that many patients with COPD do not feel comfortable talking to HCPs about their symptoms.**

**Figure 2. Timing of First Contact With an HCP When Having an Exacerbation**

Symptoms	Nobody	Half the people	Everyone
When sure something is wrong		46%	
At start of symptoms		29%	
When severe/can't handle alone		21%	
When need ER care	4%		
	0%	50%	100%

- While about 3 of every 4 (77%) 🧑🧑🧑 people with COPD say HCPs have told them to report changes in COPD symptoms, we found that most patients wait to reach out for help. As shown in Figure 2, only about 3 in 10 (29%) 🧑🧑🧑🧑🧑 say something as soon as their symptoms start to change; but almost half or 1 in 2 (46%) 🧑🧑 of people reach out only after they are sure something is wrong.
- Among those who wait to check in about a problem, about 6 in 10 (60%) 🧑🧑🧑🧑🧑 do not feel the symptoms are “bad” enough to say something.
- A little more than 1 in 3 (36%) 🧑🧑 people with COPD fear that reporting an exacerbation will put them in the hospital.
- About the same number (1 in 3 or 34%) 🧑🧑 worry that admitting they are having an exacerbation means their COPD is getting worse.
- And 1 in 10 (9%) 🧑🧑🧑🧑🧑 of people with COPD fear that reporting an exacerbation means they will get still another COPD medicine.

Overall, HCPs and people with COPD have different views on why flare-ups are not reported early. This suggests that HCPs and those with COPD are not talking about these concerns openly, providing an opportunity to improve earlier treatment of exacerbations.

#### **COPD360social members talk about exacerbations:**

*“I just know what I feel day to day, which is not as good as before the exacerbation, even with quitting smoking.”*


*“My concern is if the medication will work to bring me out of exacerbation and how long it will last. I also worry about recovery time. Seems like every time it happens it takes longer to recover.”*

*“Any infection can turn into an exacerbation, but if you catch it early enough not always an exacerbation.”*

Visits with your HCP are often short and it can be stressful to try and remember everything you wanted to talk about. In these short visits, both the HCP and you may forget how important it is to talk about how to know when you are having early problems or symptoms of an exacerbation as well as what to do and when to do it. It is also easy to forget everything that you talk about at visits, giving us another opportunity to help.

- Only 1 in 3 (34%) 🧑🧑🧑 people with COPD said flare-ups are talked about at every doctor’s visit.
- In fact, 1 in 4 (27%) 🧑🧑🧑 people with COPD said they talk even less than every other visit, which might mean only once a year.
- Apparently, both people with COPD and HCPs think talking about exacerbations is important, as both groups reported they are the ones to start conversations about these flare-ups.
- Though most people (about 7 in 10 or 71%) 🧑🧑🧑🧑🧑🧑🧑 know flare-ups have to do with their COPD, only a little more than 1 in 3 (37%) 🧑🧑🧑 know an exacerbation is “not just a bad case of the flu or bronchitis.”
- And only about 1 in 4 people (28%) 🧑🧑🧑 with COPD said they know that once they have had a flare-up, they are more likely to have another one in the future, meaning it is important to try to prevent future flare-ups.
- Tools to help with knowing when a flare-up is starting are not often shared with people with COPD. Only about 1 in 3 (39%) 🧑🧑🧑 of people with COPD said they have some type of action plan (see below) to help them during an exacerbation.

These results remind us there is room to improve our talks about flare-ups and how and why to prevent them. And available tools like the [My COPD Action Plan](#) and the COPD Foundation [patient app](#) are easily available and free to both HCPs and people living with COPD.




**COPD360action**  
IT'S MY COPD ACTION PLAN  
[www.copd360social.org](http://www.copd360social.org)

My Name: \_\_\_\_\_ Date: \_\_\_\_\_

My Doctor's Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Emergency Contact: \_\_\_\_\_ Phone: \_\_\_\_\_



**COPD**  
FOUNDATION  
[www.copdfoundation.org](http://www.copdfoundation.org)

Please complete the section above. Bring all your medicines and inhalers along with a complete list to doctor's office visits. Think about your ability to perform these activities (blue boxes) on a typical "green" day. Place one check mark in each column. In the last (blank) column write in an activity you would like to be able to do again. Check the box below it to show how difficult it is to do that activity now. Share this goal with your healthcare team and your family.

	CLEANING	MAKING MY BED	BRUSHING MY TEETH	BATHING/SHOWERING	WALKING	CLIMBING STAIRS	WORKING	SLEEPING	EXERCISING	COOKING	
I can do this											
I can do this w/ minor limitations											
I struggle to do this											
I cannot do this											

Instructions: Work with your doctor to complete this section on special medications for use on your Yellow and Red days.

My COPD Action Plan can be used daily and should be updated every 6 months. Next update \_\_\_\_\_

**My Green Days**

**A Normal Day for Me**

- My breathing is normal
- My cough and mucus are normal
- My sleeping is normal
- My eating and appetite are normal
- My activity level is normal

**Take Action**

- I will take all medications as prescribed
- I will keep routine doctor appointments
- I will use oxygen as prescribed
- I will exercise and eat regularly
- I will avoid all inhaled irritants & bad air days
- I will update my COPD Action Plan every 6 months

**My Yellow Days**

**A Bad Day for Me**

- I have a low grade fever that doesn't go away
- I have increased use of rescue medications without relief
- I have a change in color, thickness, odor or amount of mucus
- I am more tired than normal or have trouble sleeping
- I have new or more ankle swelling
- I am more breathless than normal
- I feel like I am catching a cold

**Take Action**

- I will limit my activity and use pursed-lips breathing
- I will take regular medications as prescribed
- I will report these changes to my doctor today
- I will start special medications\* prearranged with my doctor which includes: \_\_\_\_\_

**My Red Days**

**A Day When I Need Help Right Away**

- I have disorientation, confusion or slurring of speech
- I have severe shortness of breath or chest pain
- I have a blue color around my lips or fingers
- I am coughing up blood

**Take Action**

- I will call 911 right away
- I will start these special medications\*: \_\_\_\_\_

\* If symptoms are not improved in one day after taking special medications consult your doctor.  
The contents of My COPD Action Plan is for information purposes only and is not intended to be a substitute for professional medical advice, diagnosis or treatment.

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## What does this mean for you – and what can you do next?

- It is important to know all the possible signs of an exacerbation and which ones you most commonly have. Review the COPD Foundation's [Report Signs of Exacerbation checklist](#).
- Know that it is never too early to tell your HCPs about a flare-up. Most people with COPD wait to reach out to their doctor until after the exacerbation has been going on for a while. Do not wait; saying something early can help you to prevent your flare-up from getting worse or maybe prevent you from needing to go to the emergency room or hospital.
- Both doctors and people with COPD think they are the ones to bring up exacerbations, but it is clear that more talks about exacerbations would be better. Don't be afraid to speak up: if your HCP does not ask about worsening symptoms at each visit, ask them to answer your questions. These may be about what an exacerbation is, what you can do to prevent one, what a flare-up might look like for you and how best to reach your health care team in case of worsening symptoms.
- Bring up the My COPD Action Plan to your doctor. Ask to make an action plan specific to you, so that you both understand what will be done in case of a flare-up. Download a paper action plan [here](#) or use an electronic version in the COPD Foundation's COPD Pocket Consultant Guide (available for [iOS](#) and [Android](#)).

## What is next?

These results will be used to support progress to:

- Reduce the chance of COPD flare-ups.
- Help you feel more aware and in control so you can act when a flare-up starts.
- Help people with COPD to have active and helpful talks with your health care providers.