

The COPD Caregiver



The COPD Caregiver: A Crucial Person in the Patient's "Shared Care" Team

The role of the caregiver is an important one. Often, it is the greatest expression of love that can be offered. Caregiving can be hard, particularly when the person you are caring for has a progressive condition like chronic obstructive pulmonary disease (COPD). Some people become a caregiver suddenly and without warning. For others, the role evolves slowly over time. Being a caregiver for a spouse, parent, friend or other loved one takes a lot of time and work. It can also bring intellectual and emotional challenges for both the caregiver and patient. However, the situation may also strengthen the relationship. It may provide a chance to grow even closer. The attitude of the caregiver may also change the patient's attitude. A positive outlook by the caregiver can do wonders for the patient.*

It is important to realize that you're not alone – there are 65 million family caregivers nationwide. Family caregivers provide an average of 20 hours of care per week, with many providing care around the clock.

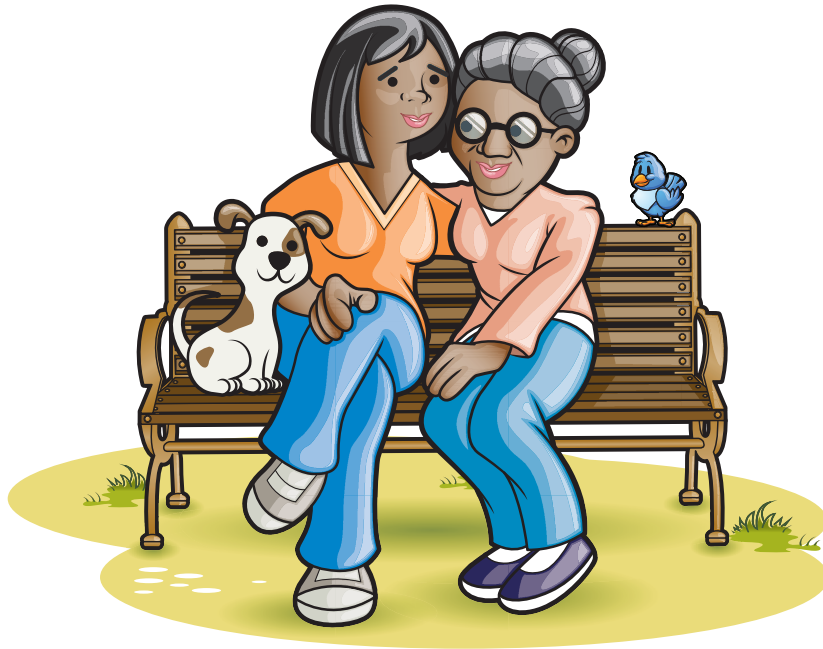
*The formal caregiver – a person paid to provide care to someone with a disability or illness – plays an important role to support a person with COPD. The language included in this booklet is made for the informal caregiver who may have less knowledge or training in providing care. These informal caregivers may include a spouse, parent, child, friend or other relative of the person with COPD.

**COPD is an umbrella term used to describe the progressive lung diseases including emphysema (em-fa-see-ma) and chronic bronchitis (kron-ick-brawn-kie-tis). People with COPD have trouble moving air in and out of their lungs because of damage to the airways and/or the air sacs.*

As a COPD caregiver, your main focus will naturally be on your loved one. However, your own well-being is vital for both of you. You must remember to take care of your own needs. Whether you recently became a caregiver or have been caregiving for a while, it's easy to get overwhelmed. You may be unsure of where to turn for information. It's also normal to have a lot of questions. You may want to know:

- Where should I look for help and support?
- How do I keep track of medication and doctor visits?
- What are the signs and symptoms that show an exacerbation (*x-saa-cer-bay-shun*) – a flare-up of my loved one's symptoms?
- How will I know when it may be time to change my loved one's disease management plan?

This guide, made in partnership with Sunovion Pharmaceuticals Inc. and the COPD Foundation, provides information, tips and resources that may help you in your role as a caregiver for someone with COPD. For more information about COPD, visit <http://www.copdfoundation.org> or www.COPDTogether.com.



What You Need to Know as a COPD Caregiver

Caregiving can disrupt that person's life. Especially in the early stages of the new relationship with the patient, it is not uncommon for both the patient and the caregiver to feel a loss of control. The patient may feel that they are becoming a burden. They may feel that they have lost self-worth because they cannot do activities that they once enjoyed. For the caregiver, the new duties can be challenging. One of the most important things you can do as a caregiver is to be informed. Educating yourself about COPD and your role can help you feel better prepared for your duties as a caregiver. It will ultimately benefit the overall health and well-being of your loved one. There are many resources available to support caregivers and help them stay informed. Family, support groups, and caregiver companies can offer services and advice (see a list of these in the next section).

Caregiving and the "Shared Care" Team

One of the best resources is your loved one's health care provider (physician, nurse practitioner or physician's assistant). Working as a team with your loved one's health care provider is helpful for both the caregiver and patient. The "shared care" treatment approach lets patients, caregivers and health care professionals work better together in helping to manage your loved one's COPD. As a caregiver, you play an important role in your loved one's shared care team. The caregiver and the patient must act as the "best advocates" for the patient's health. No one else knows how the patient is feeling daily.

Tracking COPD with your Loved One

To spot trends that might lead to an exacerbation, it is important to help your loved one track their COPD. Keeping track of medications, symptoms and disease progression doesn't have to be hard. The best solution is to use a support tool. The "COPD Care" app, developed by Sunovion Pharmaceuticals Inc. in collaboration with

COPD Foundation Recommends to Report Common Warning Signs of Exacerbations

Notify your health care provider of these early warning signs:

1. Low grade fever that doesn't go away
2. Increased use of rescue medications
3. Change in color, thickness, odor or amount of mucus
4. Tiredness that lasts more than one day
5. New or increased ankle swelling

Call 911 for dangerous or life threatening warning signs, such as:

1. Disorientation, confusion or slurring of speech
2. Severe shortness of breath or chest pain
3. Blue color in lips or fingers

the COPD Foundation, is a free app to help track COPD including symptoms, appointments and medication schedule. Tracking your loved one's COPD and noting any changes or worsening of symptoms can help you talk with the health care provider. The patient, the caregiver, and the health care provider should all be watching for trends, either good or bad, which will help show a change in the patient's condition.

To get started with the COPD Care app, visit www.COPDTogether.com.



Your Role as Caregiver in Helping To Manage COPD

By tracking symptoms and finding triggers that worsen the disease, you can also help your loved one and your loved one's health care provider recommend a treatment plan. A COPD patient's treatment plan may include pulmonary rehabilitation,

daily medical treatments and/or oxygen use. COPD medication devices need to be used in the correct way to make sure the patient receives the right amount of medicine. The caregiver should know the proper way each device is used and help your loved one as needed. If your loved one has any problems using a COPD medication device, you and your loved one can speak with his or her health care provider about considering other treatment options.

COPD is a progressive disease which means it will get worse over time. As a caregiver, it is important that you are aware of the signs of COPD progression. Some signs that COPD has become more severe include:

- Symptoms, such as shortness of breath, wheezing or chronic cough, have worsened
- Increased tiredness
- Reluctance to exercise or do activities that were done more easily
- Experiencing more frequent flare-ups and trips to the hospital or clinic to treat COPD
- An increased struggle in getting around the home, such as going up and down stairs
- Trouble doing daily activities, such as dressing or showering
- Increased depression or anxiety, especially when faced with stress of any kind

Quick Tips for Caregivers Preparing for Doctor Visits

- *Bring a daily diary of your loved one's symptoms, and how the patient responds to treatments and medications to the appointment*
- *The COPD Care app may help you and your loved one share info with the health care provider*
- *Keep your loved one's medical history as detailed as possible*
- *Make a list of any questions you and your loved one may have for the health care provider*
- *Take a notebook or even a tape recorder to learn new information*
- *Don't forget to have your loved one's insurance and Medicare cards with you*

- Not leaving home due to COPD symptoms

If you notice your loved one's COPD has gotten worse, you and your loved one should contact his or her health care provider to discuss these changes and new treatment choices.

Taking Care of Yourself as Caregiver

Remember that both the caregiver and the loved one have choices in how they approach their situation. Caregiving can be rewarding on many levels, but it can also be challenging. It is hard to see someone you are caring for struggle with their health. In addition, caregiving can change families and sometimes lead to disagreements about how best to care for the patient. There can be great sadness, hopelessness and feelings of aloneness. Caregivers can also experience much stress as the demands of caregiving take away leisure and personal time. It is not easy to stay positive despite a chronic, progressive disease, but a good attitude and a sense of humor will do wonders for everyone involved!

If the patient and caregiver can try to be kind to one another, to offer thanks for whatever thoughtfulness or efforts are offered, the burdens of all concerned can feel much lighter.

It's important to take the first step to improve the quality of life for both your loved one and yourself, and to find the support you need. By feeling better, you can help your loved one feel better. The following tips and resources can help you get started.



Is Caregiving Putting Too Much Stress on You?

With so much time devoted to caregiving it can be easy to forget about yourself. It is also easy to overlook warning signs that you're under too much stress. Common signs of caregiver stress to watch for include:

- Feeling sad or worried
- Low energy level, feeling tired
- Trouble sleeping or sleeping too much
- Gaining or losing weight
- Losing interest in hobbies or social activities
- Becoming easily angered

If You Feel Overwhelmed...

It's not unusual to feel overwhelmed as a caregiver. Talk to your family health care provider and/or clergy about your feelings. Try to take time to do something for yourself – whether it's a hobby, a phone call with a friend or just taking a long walk. Stay in touch with your friends and family members, and ask for help in giving care. Consider calling one of the companies in the next section and ask for help.

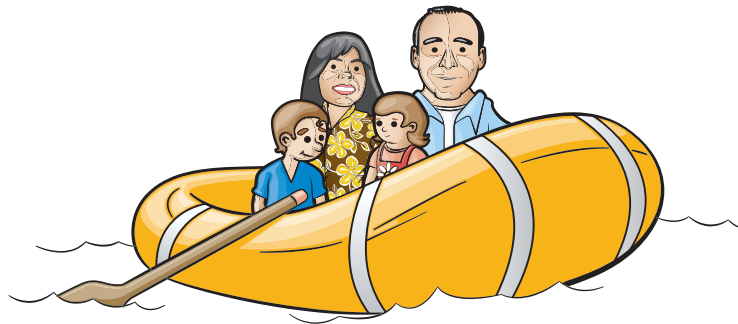
If you do not have friends or family who can help with caregiving duties, there are companies to help you with a variety of caregiving needs.

Quick Tips for Caregivers You Don't Have to "Do It All" – Where to Find Help

- *Enlist the help of friends and family. Consider hosting a family meeting to discuss what needs to be done, and divide up the jobs*
- *Keep a list of chores on hand so that other people can help when they offer it*
- *Don't be afraid to take help if it is offered. This will help lower your stress and allow you to focus on other things on your list*
- *Make lists of things to do, people to call and things to buy*
- *Keep a calendar of important dates, anniversaries, appointments, etc.*

The Call Our Patients Direct. C.O.P.D. Information Line 1-866-316-COPD (2673) can aid you with information and help in finding other resources. Some other companies that offer various services for caregivers include:

- **Eldercare Locator** can direct you to the Area Agency on Aging that serves the area your loved one lives in.
1-800-677-1116
- **The Area Agencies on Aging** can provide information on resources that serve persons aged 60 or over.
1-202-872-0888
- **Family Caregiver Alliance** can also help you find services in your community.
1-800-445-8106 or email: info@caregiver.org
- **Caregiver Resource Center** (for residents of California)
email: CRCinfo@caregiver.org
- **Visiting Angels** provides non-medical senior home care services. 1-866-739-4788
- **Caring Connections** provides free resources and information to help people make decisions about end-of-life care and services before a crisis. 1-800-658-8898
- **Hospice** provides palliative and end-of-life care, and help the patient and their family in keeping comfort, pain management and dignity. Hospicenet.org



References

Caregiver Action Network. I Just Realized I'm a Family Caregiver Now. Available at <http://caregiveraction.org/profiles/just-realized/>. Accessed: October 17, 2013.

National Alliance for Caregiving and AARP. Caregiving in the U.S. 2009. Available at http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf. Accessed: October 17, 2013.

COPD Foundation's COPD Big Fat Reference Guide. What is COPD? Available at <http://www.copdbfrg.org/> Accessed: October 17, 2013.

COPD Digest. Avoiding Acute Exacerbations of COPD. Available at <http://copddigest.org/read/164/Avoiding+Acute+Exacerbations+of+COPD>. Accessed October 17, 2013.

Global Initiative for Chronic Obstructive Lung Disease. Global Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Pulmonary Disease. Accessed: October 17, 2013

National Heart, Lung, and Blood Institute. COPD: It Has a Name: Speaker's Guide. Accessed: October 17, 2013

U.S. Department of Health and Human Services, Office on Women's Health. Caregiver Stress. Available at: <http://www.womenshealth.gov/publications/our-publications/fact-sheet/caregiver-stress.pdf>. Accessed October 23, 2013.

NOTES



Questions? Ask your PMD clinical staff.

www.sunovion.com

www.copdfoundation.org



**This booklet was created in partnership
between Sunovion and the COPD Foundation.**

About Sunovion Pharmaceuticals Inc. (Sunovion)

Sunovion is a leading pharmaceutical company dedicated to discovering, developing and commercializing therapeutic products that advance the science of medicine in the Psychiatry & Neurology and Respiratory disease areas and improve the lives of patients and their families.

Sunovion, an indirect, wholly-owned subsidiary of Daiippon Sumitomo Pharma Co., Ltd., is headquartered in Marlborough, Mass. More information about Sunovion Pharmaceuticals Inc. is available at www.sunovion.com.

About the COPD Foundation

The COPD Foundation's mission is to prevent and cure Chronic Obstructive Pulmonary Disease and to improve the lives of all people affected by COPD. For more information call 1-866-316-COPD (2673).

Take Action Today. Breathe Better Tomorrow.

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