

# The COPD Caregiver's Toolkit: Findings from a Regional Study

June 2019





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## 1. INTRODUCTION

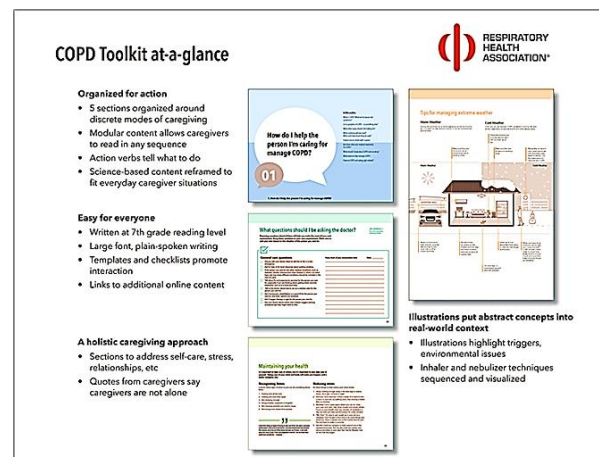
### Background

Approximately 16 million people in the United States are currently diagnosed with COPD and millions more have the disease but have not yet been diagnosed.<sup>i</sup> COPD accounts for the majority of deaths from chronic lower respiratory diseases and is the fourth leading cause of death in the U.S.<sup>ii</sup>

While much attention has been paid to the medical and support needs of people living with COPD, less time has been devoted to considering and addressing the needs of their informal caregivers. In many cases these are family members who possess strong personal and emotional connections with the persons living with COPD but often lack training on how to best support their loved ones.

Through its extensive work with the COPD community<sup>iii</sup>, RHA has identified a significant gap in educational and support resources dedicated to informal caregivers. Specifically there are no comprehensive, user-centered caregiver support tools and resources that are grounded in health theory. In response to this need, in 2017 RHA developed, with support by Institute of Design at Illinois Institute of Technology, a novel, comprehensive COPD caregiver support tool (“The COPD Caregiver’s Toolkit” or “The Toolkit”). The Toolkit is organized into five sections (described below) each addressing a different aspect of caregiving.

In 2018, with support from the National Heart Lung and Blood Institute’s Learn More Breathe Better Program, RHA launched a study of caregivers’ acceptance of the COPD Caregiver’s Toolkit and their perceptions of the degree to which the Toolkit helped in carrying out their responsibilities. This report summarizes the findings of RHA’s study.



### Approach

Between August and October 2018, 215 Toolkits were given to providers at Illinois pulmonary rehabilitation groups and clinical practices in Illinois, Indiana, Michigan and Ohio. These providers distributed 95 toolkits to informal COPD caregivers between August and October 2018. Caregiver participants were surveyed three months after receiving the Toolkit and eight caregivers also participated in one of two focus groups. Several participants did not complete the survey for a variety of reasons, including their own hospitalizations, the

death of their care recipient, and simply not wanting to take the survey. Including surveys collected at the focus group, RHA received a total of 36 surveys.

## 2. FINDINGS

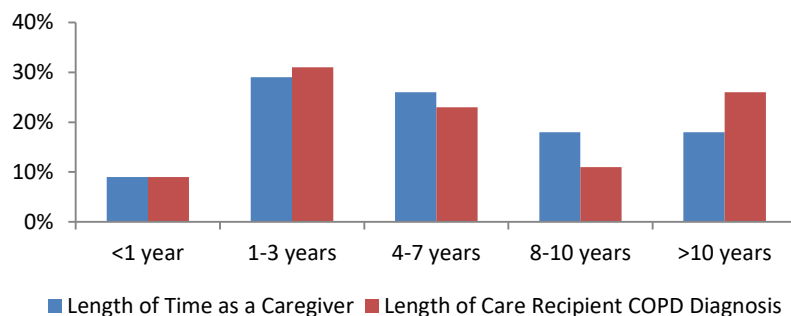
### Caregiver Characteristics and Demographics

**Caregiver Demographics:** The 36 participating caregivers had an age range of 36-92 years old, with an average age of 68 years old. Caregivers were more likely to be female, non-Hispanic white, married, and retired. All participants had at least a grade 12 or GED education or higher. Caregivers reported a wide range of incomes; 37% of participants reported an annual household income of less than \$50,000, while 37% of participants reported an income above \$50,000 (with 26% not reporting income). Participants mainly reported being spouses/partners of the care recipient (58%), although, it should be noted that 17% of participants reported serving as their own caregiver.

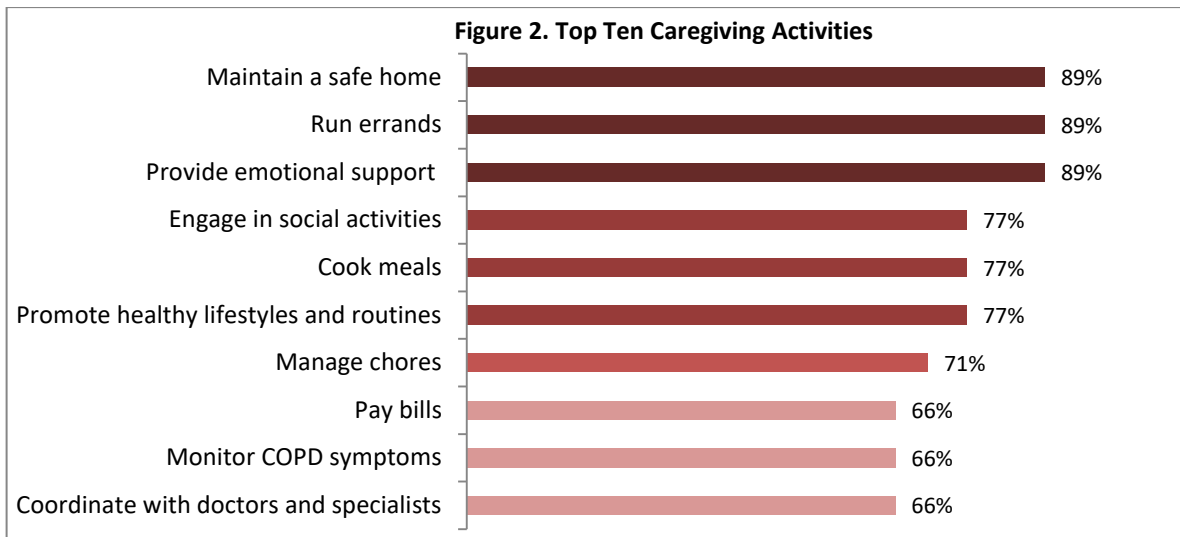
**Caregiver Characteristics:** While caregivers were mainly retired (67%), over one-third (39%) reported they spent 24 hours/7 days a week caring for their loved one with COPD. Most caregivers provided support alone; 61% of caregivers reported that they did not have additional assistance (e.g., a home health aide) in providing care.

Participants had a range of experiences in informal caregiving. Over half of caregivers (55%) had spent between one and seven years providing care. Similarly, 54% of care recipients were reported to have had the COPD diagnosis for the same length of time. A majority of caregivers (80%) lived at home with their care recipients.

**Figure 1: Years as Caregiver and Patient Time Since Diagnosis**



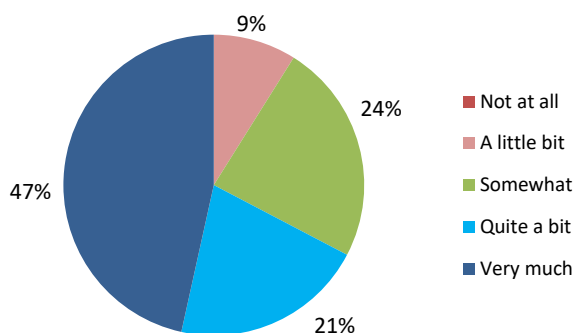
**Caregiving Activities:** Participants were asked about the activities they perform as a caregiver. The top ten activities reported, which were activities performed by at least 66% of caregivers, are shown below in Figure 2. These top activities show that caregivers play multiple roles, ranging from coordinating with doctors and specialists to maintaining a safe home environment. Other activities, in addition to those in Figure 2, include coordinating home services, coordinating with insurance providers, advocating for services and support, setting up and maintaining medical equipment, managing medical tests and testing, providing and managing medication and treatments, making doctor's appointments, and arranging or providing transportation.



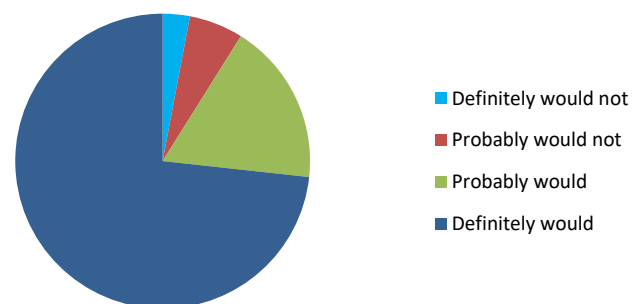
### Usefulness of the Toolkit

A majority of caregivers read and found the Toolkit useful; eighty-two percent (82%) reported that they had read either most or all of the Toolkit, and 68% found the Toolkit helpful from the perspective of someone caring for a person with COPD. The vast majority of caregivers (92%) stated they would definitely or probably recommend the Toolkit to someone else. In fact, caregivers shared that the Toolkit should be distributed early in the care recipient’s COPD diagnosis and caregiving journey. For example, one caregiver shared, “It would be nice to have had this a couple years ago.” Another explained, “The earlier you can get this in the hands of somebody, the better, so then everybody knows what they’re in for.”

**Figure 3: Helpfulness of Toolkit**



**Figure 4: Recommending Toolkit to Someone Else**

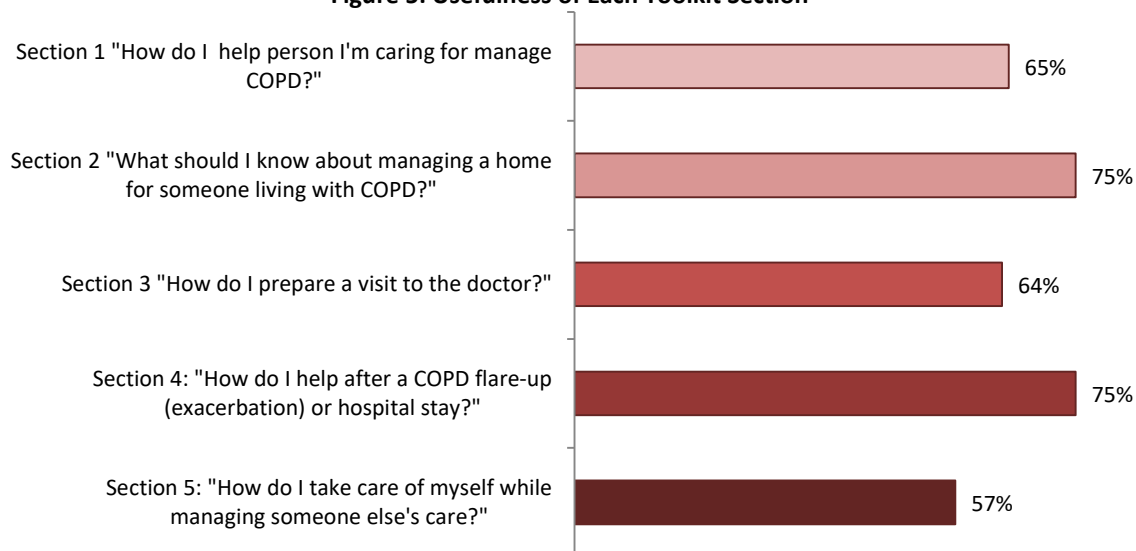


### Sections of the Toolkit

As previously noted, the Toolkit’s five sections are designed to address different needs faced by caregivers. Caregivers generally found the sections of the Toolkit to be useful. More caregivers (75%) found the sections “What should I know about managing a home for someone living with COPD?” and “How do I help after a

COPD flare-up (exacerbation) or hospital stay?” to be the most useful toward their caregiving duties. Caregivers did not report finding the section “How do I take care of myself while managing someone else’s care?” as helpful—only 57% of caregivers reported it as useful. However, when caregivers were prompted to give qualitative responses about the most helpful and least helpful aspects of the Toolkit, many responded that all of the sections were helpful.

**Figure 5: Usefulness of Each Toolkit Section**



***Managing a home for someone living with COPD:*** Caregivers found Section 2, “What should I know about managing a home for someone living with COPD?” to be one of the most useful sections. This is not too surprising as most participating caregivers live with their care recipient (80%). Caregivers also identified multiple activities related to maintaining as safe home as a major part of their caregiving role, with the most caregivers (89%) indicating “maintaining a safe home” as one of their main caregiving duties. One caregiver talked about how she changed the way in which she maintained the care recipient’s home after reading this section.

*“What I thought was very helpful was when they tell you how to make the home safer because for some reason he stays in a studio, so it’s kinda cramped, and he feels better when he goes outside than inside the apartment. So I try to vacuum every day and dust and you know keep it freshened up in there, and you know he can’t take a lot of spray so I have to do all that while he’s gone. So I found that very helpful.”*

**How to help after a COPD flare-up or hospital stay:** Caregivers also found Section 4, “How do I help after a COPD flare-up (exacerbation) or hospital stay?” to be one of the most useful sections. Caregivers, in particular, found the power of attorney information in this section to be useful.

Caregivers also found the information on managing COPD flare-ups and how to help loved ones after flare-ups to be useful. Another caregiver shared that this information was the most helpful in managing someone’s COPD because “flare-ups [were] more common than expected.”

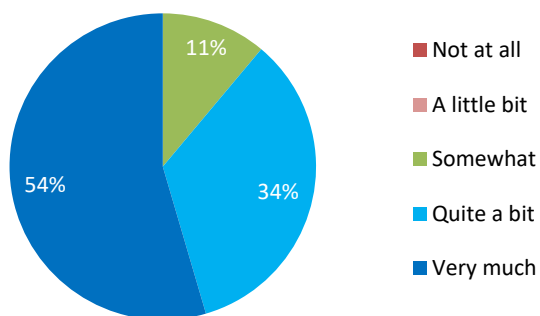
**Taking care of myself while managing someone else’s care:** Given that caregivers often put the needs of their care recipients above their own, it is not surprising that just 57% of the caregiver participants found the section “How do I take care of myself while managing someone else’s care?” less useful than all of the other sections. However, when asked in both the qualitative portion of the survey and focus groups, caregivers stressed the importance of the self-care section. Caregivers would describe benefits to their own health and relationships with care recipients after reading that section.

*“There was a craft show I wasn’t gonna go to because I figured there’d be a couple more hours with him at home, and [after reviewing the Toolkit] I thought well, I’m supposed to do things that are fun for me too, so I’m gonna go...When I do little things like that I come back and it’s like we’re sorta, I mean this sounds terrible, but it’s like we’re nicer to each other just from getting away a little bit”.*

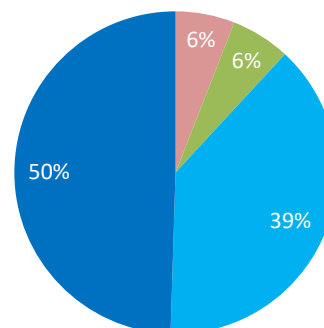
### Toolkit Understanding & Relevance

The vast majority of caregivers (94%) thought the print size of the Toolkit was just right. More than half of the caregivers (53%) reported that they would not use an electronic version if it were offered. Caregivers felt the information in the Toolkit was relevant (89%) and included the right amount of detail (97%). Caregivers reported that they mainly understood the information in the Toolkit (89%). All caregivers (100%) felt there was no information provided that did not need to be included and 82% felt there was no information missing.

**Figure 6: Understanding the Toolkit**



**Figure 7: Toolkit Relevance**



The Toolkit provided COPD caregivers a sense of confidence and comfort in their caregiving role. Several caregivers shared that they kept the Toolkit in a specific place in their homes and made sure that both family members and the care recipient knew where it was located in case of an emergency. This enhanced their confidence and comfort should anything happen to the caregiver.

*“I used it [the Toolkit] for making sure that if an emergency comes into the house that it is in visible sight because my husband wouldn’t remember where it is and I wouldn’t remember where it is probably.”*

### 3. KEY THEMES

#### More Attention Is Needed for Caregivers’ Self-Care

When reviewing responses across survey sections, what is most compelling is the need to reinforce to caregivers that they must take care of themselves. Despite reporting that they found the Toolkit’s self-care section to be the least useful of all sections, responses underscored the need for it. Findings revealed that over one-third of caregivers (39%) are providing round-the-clock (24/7) care to their loved one, and nearly two-thirds of caregivers (61%) have no outside assistance in doing so.

In addition to the physical toll of caregiving, the caregiver’s emotional health and well-being must be considered as they carry out their role. Caregivers reported managing the emotional health of their care recipient as one of their top roles. They achieved both by providing emotional support (89%) and engaging them in social activities (77%).

For some participants, having a section on self-care helped them gain perspective on their role and the sacrifices they have made as caregivers. For others, it helped them recognize and feel more comfortable taking time for themselves and focusing on their own emotional and physical health.

*“Just reading [the Toolkit] makes me feel less guilty if I want to do something. Because sometimes I feel guilty like oh, should I really go to that or should I stay home? But then when [the Toolkit] said about well, you gotta do things that you enjoy too, it’s like oh I guess I can go out and feel okay about it because the book says I can go out.”*

*“I really like the section with the many roles of the caregiver. I hadn’t thought about all the stuff that I do for him until yep, I do that, do that...It kind of made me feel better...it made me realize that the choice I made giving up my career to be there for him was because I was doing all of this and that’s why I was getting so stressed at work because I was trying to do all this and a job.”*



## The Toolkit is Meeting a Need for Caregivers

As noted earlier, the usefulness of each of the five Toolkit sections varied from 75% (managing a home and how to help after a COPD flare-up) to 57% (caregivers' self-care). When asked how helpful they found the Toolkit overall, over two-thirds of participating caregivers (68%) found the Toolkit "quite" or "very" helpful for their caregiving duties (68%), and another 24% reported the Toolkit was "somewhat" helpful. Further, a majority of participating caregivers 89% found the information provided to be "quite" or "very" relevant. These findings, coupled with the fact that 91% of participants had been caregiving for over one year (and 62% for over four years), suggest that the need for new information and supportive resources remains.

The ways in which the Toolkit's guidance was operationalized by participating caregiving varied greatly. These included vacuuming and dusting on a daily basis, organizing their papers (e.g. power of attorney and medication lists), and taking time for themselves.

## 4. MOVING FORWARD

Based on the survey findings and the input of health care providers who distributed the Toolkit, several next steps are planned.

- Development of a training or webinar for health care providers: The training will be targeted to clinicians and other health care providers who plan to distribute the Toolkit. It will provide guidance on how to introduce the Toolkit to patients and their informal caregivers and how to use the Toolkit most effectively. Given the findings above, the training will include the need to emphasize the section on how caregivers should care for themselves.
- Creation of a User's Guide: RHA will develop a one-page guide to accompany the Toolkit. It will provide instructions for how informal caregivers can best use the Toolkit and integrate it into ongoing caregiving activities.
- Broader distribution: RHA plans to distribute the Toolkit to a larger audience. Based on survey responses, distribution will focus on caregivers of newly diagnosed COPD patients and those of patients recently hospitalized due to a COPD exacerbation. Participating health care providers advised that the best locations to distribute the Toolkits include primary care office settings, pulmonary function labs, and in in-patient settings. RHA also recognizes that because caregivers often don't accompany their care recipients to respiratory therapy appointments, less attention should be focused on these sites for distribution.

*I have a place and I told everybody in my family where it [the Toolkit] is in case they're called, and I just feel so comfortable knowing that everything is in its place. His blood work, his medications, power of attorneys, the last doctor's report that I get from the doctor, when he goes to the doctor, I put in the toolkit and then I take the old one out. The medications, I have it in several pockets because I think that's so important. The hospital knows his medications, but they don't always get it right."*

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<sup>i</sup> National Heart, Blood, and Lung Institute. <https://www.nhlbi.nih.gov/health-topics/copd>

<sup>ii</sup> Centers for Disease Control and Prevention. Mortality in the United States, 2017  
<https://www.cdc.gov/nchs/products/databriefs/db328.htm>

<sup>iii</sup> For more information on RHA's COPD efforts, visit [www.resphealth.org/COPD](http://www.resphealth.org/COPD)

**Acknowledgments:**

*RHA acknowledges the National Heart, Lung and Blood Institute (NHLBI) for supporting this project through its COPD Learn More Breathe Better initiative. RHA also acknowledges Sara Shaunfield, PhD and Susan Yount, PhD, from the Department of Medical Social Sciences at Northwestern University Feinberg School of Medicine, for their help with designing data collection tools and conducting data analysis.*

For more information on RHA's COPD efforts please visit [www.resphealth.org/COPD](http://www.resphealth.org/COPD) or contact Avanthi Chatrathi at [Achatrathi@resphealth.org](mailto:Achatrathi@resphealth.org)