

Official Title:	Pair 2 Care: Peer Support for Caregivers of Black Americans Living With Dementia
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3                   **The Ohio State University Consent to Participate in Research**

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**Study Title:** Pair 2 Care: Peer Support for Caregivers of African Americans Living with Dementia

**Protocol Number:** 2023B0071

**Researcher:** Karen O. Moss, PhD, RN, CNL

**Sponsor:** Cambia Health Foundation Sojourns Scholars Leadership Award

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8                   **This is a consent form for research participation.** It contains important  
9                   information about this study and what to expect if you decide to participate.

10                  **Your participation is voluntary.**

11                  Please consider the information carefully. Feel free to ask questions before  
12                  making your decision whether or not to participate.

13  
14                  **Purpose:** The purpose of this study is to test a peer support  
15                  program/intervention for caregivers who are caring for a loved one living with  
16                  dementia. The program/intervention is called Pair 2 Care: Peer Support for  
17                  Caregivers of African Americans Living with Dementia.

18  
19                  **Procedures/Tasks:**  
20                  A total of 15 people who are currently caring (current caregivers) for a loved  
21                  one living with dementia and a total of 15 people who cared for (former  
22                  caregivers) a loved one who lived with dementia will be included in this study.  
23                  Former caregivers will complete up to two 1-hour training sessions over Zoom<sup>®</sup>  
24                  to become mentors to current caregivers (mentees). Former caregivers will be  
25                  called 'mentors' and current caregivers will be called 'mentees'. Each mentor  
26                  and mentee will be paired for 6 months for peer support. We will attempt to  
27                  pair mentors and mentees based on something they have in common. During  
28                  the Pair 2 Care program/intervention, mentors will provide non-judgmental,  
29                  flexible, culturally sensitive support to their mentees and share their personal  
30                  caregiving experiences. Information collected during the screening process  
31                  such as the type of family caregiver you are may be included as study  
32                  information from participants once they are consented.

33

34 At the beginning of the study, we will ask you to provide us with your phone  
35 number so we can add it to our participant communication system, called  
36 Twilio. While you are in the study, we will communicate with you via text  
37 messaging. Please note that you will not pay any additional charges for this  
38 service over and above what you normally are charged by your mobile network  
39 provider for sending and receiving any text messages or transmitting/receiving  
40 any data. When you are no longer in the study, we will stop sending you text  
41 messages. At any point, if you reply to a message with STOP or QUIT, you will  
42 no longer receive messages from the system. Our research team is also able  
43 to help you "opt out" of the messaging service through the system.

44

45

46 **Duration:**

47

48 During this research study we will contact you to ask you to provide answers to  
49 short surveys about yourself and your loved one living with/or who lived with  
50 dementia. As mentees, you will complete surveys at the beginning, at 3  
51 months, 6 months, and at 1-month follow-up. Completion of these surveys  
52 should take about 1 hour each time. A member of the research team will  
53 connect with mentees regularly for feedback on how the mentoring process is  
54 going. During the research study mentees will receive text, email, and/or  
55 phone call reminders to ensure you are connecting with your mentor and to  
56 schedule and remind you of when we have appointments to complete the  
57 trainings (mentors only) surveys and the interview (mentees only). One month  
58 after the study is completed, mentees will also complete an audio-recorded 1-  
59 hr interview about the experience of being in Pair 2 Care. This interview will be  
60 audio recorded using two voice recorders. You can choose not to answer any  
61 question that you do not wish to answer. We will do these surveys and the  
62 interviews either over the telephone or video call.

63

64 During the Pair 2 Care research study, we will ask you to connect with your  
65 mentor/mentee for at least five virtual face-to-face (video) calls (using e.g.,  
66 Zoom<sup>®</sup> or FaceTime<sup>®</sup>) and at least 10 other interactions either via phone call,  
67 email, or text messaging. You will use your regular mobile phone service to  
68 text your mentor/mentee. When you connect with your mentor/mentee, feel  
69 free to discuss caregiving-related topics such as any of the following:  
70 *accessing/selecting healthcare providers, attending doctor visits, attending*  
71 *worship services, coronavirus pandemic/endemic, exercise, faith, family*  
72 *dynamics, finances, healthcare decision making, mental health, nutrition,*  
73 *physical health, sleep, social activities, spirituality, managing multiple*  
74 *responsibilities, respite care, self-care, social support, work (inside and outside*

75 *of the home), activities of daily living, attending public events, adult daycare,*  
76 *advance care planning, assistive devices, coping with dementia-related*  
77 *behavioral symptoms, end-of-life planning, financing care, hospitalizations,*  
78 *mobility, nursing homes, nutrition, palliative care, hospice, support*  
79 *services/resources, skin care, urinary incontinence.* Once each week during  
80 the 6 months connection, mentees will be sent a short survey by text or email  
81 to complete about their connection with their mentor during the last week. This  
82 information may also be received over the phone by a researcher. If not done  
83 by the mentee, a text, email and/or phone call will be sent/made a couple days  
84 after as a reminder to do it.

85  
86 Mentors in this study are not health or healthcare experts, therefore, mentees  
87 will be reminded to get call or visit a healthcare provider for all health and  
88 safety issues. This includes calling 911 for all emergencies.

89  
90 If you are unable to contact your peer mentor or mentee after four (4) tries, we  
91 ask that you do not make any more attempts to reach them and let a study  
92 team member know. The team member will try to reconnect you with your peer  
93 mentor or mentee and then let you know what will happen next.

94  
95 You may leave the study at any time. If you decide to stop participating in the  
96 study, there will be no penalty to you, and you will not lose any benefits to  
97 which you are otherwise entitled. Your decision will not affect your future  
98 relationship with The Ohio State University. If your mentor or mentee is unable  
99 to stay in the study for any reason you may be allowed to continue being in the  
100 study.

101  
102 **Risks and Benefits:**

103  
104 The risks for harm to you for participating in this study are minimal.

105  
106 Discussion about your loved one may make you feel sad. It may include  
107 discussions about healthcare decisions, end-of-life decision making, grief,  
108 loss, death, and dying. We might suggest that you see your primary healthcare  
109 provider and have included a list of Mental Health Resources to contact for  
110 additional follow-up if needed. Cost for these additional services will not be  
111 covered by the research study.

112  
113 If you learn about or have any health or safety concerns about your mentor/  
114 mentee or their loved one, please contact a study team member as soon as  
115 possible who will report it to the study leader. The study leader is a mandated

116 reporter and is therefore required by the state of Ohio to report abuse. The  
117 study must notify the relevant authority for safety concerns and the research  
118 ethics board.

119  
120 If you choose to leave the study or are asked to leave the study at any time for  
121 any reason, you will be asked not to be in contact with your mentor or mentee  
122 for any further study-related activities.

123  
124 There are no specific benefits to you from being in the study. The knowledge  
125 gained in the study will help us to make the Pair 2 Care program/intervention  
126 better. There are no costs to you for participating in this study.

127  
128 **Confidentiality:**  
129  
130 We will work to make sure that no one sees your online responses without  
131 approval. But, because we are using the Internet, there is a chance that  
132 someone could access your online responses without permission. In some  
133 cases, this information could be used to identify you.

134  
135 Also, there may be circumstances where this information must be released.  
136 For example, personal information regarding your participation in this study  
137 may be disclosed if required by state law. Also, your records may be reviewed  
138 by the following groups (as applicable to the research):

- 139 • Office for Human Research Protections or other federal, state, or  
140 international regulatory agencies;
- 141 • The Ohio State University Institutional Review Board or Office of  
142 Responsible Research Practices;
- 143 • Authorized Ohio State University staff not involved in the study may be  
144 aware that you are participating in a research study and have access to  
145 your information; and
- 146 • The sponsor, if any, or agency (including the Food and Drug  
147 Administration for FDA-regulated research) supporting the study.

148  
149 Audio recordings will be stored on an encrypted (secured), password protected  
150 computer. Once checked for accuracy and examined, the audio will be  
151 destroyed by erasing the electronic recording.

152  
153 **Future Research:**  
154  
155 Your de-identified information may be used or shared with other researchers  
156 without your additional informed consent.

157

**158 Incentives:**

159

160 By law, payments to participants are considered taxable income. You will  
161 receive a \$25 gift card and thank you note (electronically or by mail) each time  
162 a set of surveys, mentee interview, or mentor training is completed. Current  
163 caregivers (mentees) will complete surveys in the beginning, 3 months, 6  
164 months, and 1-month follow-up. The 1-month follow-up will include an audio-  
165 recorded interview. Former caregivers (mentors) will complete surveys in the  
166 beginning, training, and 3-months and 6-months check in. You will receive a  
167 total of \$100 over the time of the study. Once the study results are completed,  
168 and you chose to, you will receive a letter with the results of the study. Gift  
169 cards will be sent either electronically (text message or email) or by mail via a  
170 secure service called Virtual Incentives<sup>®</sup> depending on which one you prefer.  
171 We will provide Virtual Incentives<sup>®</sup> your name, mailing address, phone and/or  
172 email address. Virtual Incentives<sup>®</sup> will not share your information with others.  
173 There is no cost to you for using this service.

174

**175 Participant Rights:**

176

177 You may refuse to participate in this study without penalty or loss of benefits to  
178 which you are otherwise entitled. If you are a student or employee at Ohio  
179 State, your decision will not affect your grades or employment status.

180

181 If you choose to participate in the study, you may discontinue participation at  
182 any time without penalty or loss of benefits. By agreeing to participate, you do  
183 not give up any personal legal rights you may have as a participant in this  
184 study.

185

186 An Institutional Review Board responsible for human subjects research at The  
187 Ohio State University reviewed this research project and found it to be  
188 acceptable, according to applicable state and federal regulations and  
189 University policies designed to protect the rights and welfare of participants in  
190 research.

191

**192 Contacts and Questions:**

193 For questions, concerns, or complaints about the study, or you feel you have  
194 been harmed as a result of study participation, you may contact **Dr. Karen**  
195 **Moss at 614-688-3100 or moss.391@osu.edu.**

196

197 For questions about your rights as a participant in this study or to discuss other  
198 study-related concerns or complaints with someone who is not part of the  
199 research team, you may contact the Office of Responsible Research Practices  
200 at 1-800-678-6251 or [hsconcerns@osu.edu](mailto:hsconcerns@osu.edu).

201  
202 **Providing consent**  
203

204 I have read (or someone has read to me) this page and I am aware that I am  
205 being asked to participate in a research study. I have had the opportunity to  
206 ask questions and have had them answered to my satisfaction. I voluntarily  
207 agree to participate in this study. I am not giving up any legal rights by  
208 agreeing to participate.

209  
210 To print or save a copy of this page, select the print button on your web  
211 browser.

212  
213 In order to provide your verbal consent, you will tell the research team member  
214 your responses to the following questions. In order to be in this study, you  
215 must respond 'Yes' to question #1:

- 216  
217 1. "Do you agree to participate in the Pair 2 Care: Peer Support for  
218 Caregivers of African Americans Living with Dementia Research Study?  
219 YES or NO
- 220  
221 2. "Is it okay for me to record the audio during the interview?" YES or NO
- 222  
223 3. "When the study is completed, would you like to receive a copy of the  
224 study results?" YES or NO
- 225  
226 4. "Would you like to be contacted about the chance to be in other  
227 research studies?" YES or NO