

Building Better Caregivers™ An Online Workshop for Caregivers

The free online workshops begin January 2012. Register at www.caregivers.selfmanage.org

Family Caregivers perform a variety of tasks for people with memory issues, from bathing to medication administration to symptom monitoring to dealing with behaviors. These responsibilities can become frustrating and exhausting and can even lead to poor health for the caregiver. The online Building Better Caregivers (BBC) workshop addresses the needs of those looking after their family members or friends with cognitive difficulties such as dementia, traumatic brain injury, post traumatic stress disorder, or memory problems. The workshop is designed to help them to be physically and emotionally balanced and healthy. The project underway in Idaho will provide the workshops to caregivers of older persons with dementia, particularly Alzheimer's Disease.

How It Works

The Building Better Caregivers program, developed at Stanford University, is a six-week workshop offered on a dedicated website. Workshops consist of 15-25 persons per workshop. BBC does not require "real time" attendance (i.e., there are bulletin boards rather than chat rooms).

The workshop is facilitated by two trained facilitators, one or both of whom are also caregivers. In the program, facilitators and participants together address a number of topics, including: stress management, difficult care partner behaviors, sleep, healthy eating, exercise, difficult emotions, care partner emotions, making decisions, finding help and making plans for the future.

Participants are asked to log on two to three times a week for a total of one to two hours. Weekly activities include reading and interacting via the Learning Center, making and posting a weekly action plan, participating in problem solving and guided exercises on bulletin boards, and participating in any appropriate self-tests and activities. Participants are encouraged to post problems on a bulletin board and help other group members with their problems.

The Learning Center contains the primary content of the workshop, and is where participants learn techniques to help them manage their complicated lives and maintain their own emotional and physical health. Each week, new content will be made available. Past weeks' content will also remain available. The Learning Center is self-directed in that participants can control the speed and timing of their progress. In addition to the Learning Center, there are four other areas of the workshop's website, which are reflected on the menu bar. The four sections include the following:

- The Discussion Center is interactive and includes four directed bulletin boards: the action-planning board, the problem-solving board, the difficult emotions board, and the celebrations board.
- Additionally, participants wishing to communicate with each other individually may do so through the Post Office, which is an internal messaging system.
- My Tools is a personal area accessible only by the participant and contains such tools as journals, exercise monitoring logs, and medication records.
- Help is where participants can take a tutorial on how to use the workshop and learn computer skills such as how to scroll and use pop-up windows. Help also contains e-mail links to the facilitators and other online staff. In addition, My Tools contains a glossary, a review of workshop guidelines, and privacy policies.

Using the menu on each web page, participants can move between these five areas as they wish.



Broadly Accessible

BBC has been designed so that it can be used by almost anyone who has access to the Internet, including those that do not have access to broadband. For this reason, video clips and extensive graphics are not used. The program is compatible with Internet Explorer, Netscape, Safari, Foxfire and AOL web browsers and can be used with Windows and Macintosh platforms.

Demonstrated Outcomes

Stanford conducted a longitudinal study on this program. At 3 months, caregivers showed significant reductions in caregiver burden, depression, pain and stress. Caregiver self-efficacy and two exercise measures improved. The care partners' overall health improved. The program successfully reached rural residents and participation was high.

Rich Content

The following is a session-by-session overview of the content:

| Workshop Overview | | | | | | |
|------------------------------------|--------|--------|--------|--------|--------|--------|
| | Week 1 | Week 2 | Week 3 | Week 4 | Week 5 | Week 6 |
| Self-Management overview | ✓ | | | | | ✓ |
| Stress Management | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Problem Solving | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Action Planning | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Difficult Care Partner Behaviors | | ✓ | ✓ | ✓ | ✓ | ✓ |
| Sleeping Well | | ✓ | | | | |
| Healthy Eating | | | ✓ | ✓ | | |
| Exercise | | | ✓ | ✓ | | |
| Difficult Emotions | | | ✓ | ✓ | ✓ | ✓ |
| Care Partner Emotions | | | ✓ | ✓ | ✓ | ✓ |
| Making Decisions | | | | ✓ | ✓ | |
| Finding Help | | | | | ✓ | |
| Communication | | | | | ✓ | |
| Working with the Healthcare System | | | | | ✓ | ✓ |

| | | | | | | |
|-----------------------------------|--|--|--|--|---|---|
| Working with Healthcare Providers | | | | | ✓ | ✓ |
| Medication Management | | | | | | ✓ |
| Making Plans for the Future | | | | | | ✓ |

Fostering Self-Efficacy

As in other Stanford programs, BBC helps participants gain a sense of control over their lives through enhanced self-efficacy. This includes guided mastery experiences, acquisition of skills and enhancement of self-confidence through peer modeling, reinterpretation of symptoms, and social persuasion.

Skills mastery: Participants create a weekly action plan and try new behaviors such as taking a regular walk, researching respite options, logging his/her reaction to difficult care partner behaviors, or engaging in a relaxation exercise. Each session includes a place for feedback on progress and discussion of problems.

Modeling: To enhance the connection between participants and facilitators, at least one of the two peer facilitators for each BBC program must be a caregiver. The program offers structured opportunities for participants to support each other, with problem solving via bulletin boards. Thus, participants model for each other and, by serving as models, enhance their self-efficacy. Finally, workshop members are asked to check in with each other via the Post Office between class meetings.

Exploration of Care Partner Behaviors: Difficult care partner behaviors are often the most challenging aspects of caregiving. By looking at these behaviors in other ways, strategies for dealing with both the behaviors and the caregiver’s reaction to them can be explored. For example, if the care partner becomes angry because lunch is late, the caregiver may believe that it is because the care partner is unreasonable. By looking at the behavior, what came before it, what triggered it, and the caregiver’s response, other causes may be discovered, such as the care partner may be bored. By seeing other possibilities, the caregiver can then develop some strategies to deal with the behavior and their reaction to it.

Social Persuasion: Participants are urged to share their action plans and other workshop activities with family and friends in order to create a supportive environment for change. In addition, facilitators urge participants to do a little more than they are doing now. Finally, the use of bulletin boards and the Post Office assist group members to interact with and support each other.

Facilitators

Peer facilitators serve as influential role models for promoting self-management skills and self-efficacy. Two trained facilitators moderate each BBC workshop. Their role is to facilitate the discussion and to act as a role model. They do not teach content. They see that participants log on to weekly learning modules and discussion areas, and send them e-mails if this does not happen. In addition, they monitor and stop any inappropriate posts. They never offer individual medical advice and if asked about this either directly or through the discussion boards, they advise participants to seek the answer from their health care provider. Facilitators monitor all discussion boards daily and if a program participant offers medical advice to another, the facilitator will caution that it is best to check this out with health care providers and will also notify program staff.

All facilitators follow a protocol that provides detailed guidelines for the conduct of the program. All programs are moderated daily. This means that at least one of the facilitators will read all new posts, assist program participants with problem solving, and report any difficulties to the project staff. (Project staff are available to facilitators online seven days a week.) All facilitator training is conducted online. To validate the consistency of moderation and as a quality control, NCOA staff randomly observes at least 25% of the workshops.

Recruitment

Recruitment of both facilitators and participants may be done either by NCOA or by sponsoring organizations. NCOA works with the sponsoring organization to determine the best participant recruitment strategy for their population. It should always have an online component and take advantage of other communication vehicles and trusted sources when appropriate.

How does a participant travel through BBC?

Potential participants express interest through an online registration process. When there are enough people expressing interest to fill a workshop (about 25 people), a workshop is formed. Potential participants are told that they will be contacted about the start date of the next workshop.

Approximately two weeks before the start of a workshop, the interested individuals are e-mailed an invitation to enroll on a secure website. After reading and agreeing to the informed consent, potential participants fill out a questionnaire, which contains demographic questions, and possibly screening questions, depending upon the client organization's preferences. Participants are not able to proceed without completing the consent form. They must also complete the questionnaire, although many of the questions are optional. Once participants have completed both the consent form and questionnaire, they are entered into the system and sent the program materials.

All participants are sent email information on how to enroll in their workshop and participate in the workshop for up to eight weeks. The actual workshop is six weeks, but the site may be made available for each workshop for an additional two weeks so that participants can continue communicating with one other after the didactic portion of the workshop ends.

If the client organization opts for a clinical trial or study, the participants will be contacted again at the first interval (typically six months after they began the program), when they will be sent information via email on how to access their online follow-up questionnaire (if the client so chooses to have one administered). Each participant will receive up to four reminders by email, mail, and/or phone to complete the questionnaire. This process is/can be repeated at a second interval, usually 12 months after baseline.

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If you would like more information about the Building Better Caregivers program in Idaho, please contact Pam Catt-Oliason, Program Specialist, Idaho Commission on Aging, 208-577-2852, pam.catt-oliason@aging.idaho.gov

