

APHASIA BOOK CLUBS: MAKING THE CONNECTION

by Roberta J. Elman, Ph.D., CCC-SLP, BC-ANCDS
and Ellen Bernstein-Ellis, M.A., CCC-SLP, members
American Speech-Language-Hearing Association



Wednesday morning visitors to the Aphasia Center of California (ACC) might be surprised to see a group of stroke survivors with aphasia eagerly debating and laughing about what they had read the previous week from a *New York Times* bestseller. But participants in the ACC's Book Connection™ program are once again reading for pleasure. The Book Connection program began when our ACC members told us they wanted to read.

We wondered how we might adapt a book club to make it both accessible and enjoyable to people living with aphasia. Our challenge was to figure out a way to create a book club for people with all types and severities of aphasia.

Seven years, 15 popular books and thousands of hours of hard work later, we have learned an enormous amount about creating book clubs for people with aphasia. Our ACC members taught us that it wasn't critical that they be able to read and understand every word, but rather that they could enjoy whatever they read or listened to on audiotapes. We also learned that they preferred to read what their friends were reading. Favorite books have been ones with strong elements of humor or optimism.

In 2004, we received funding from the Langeloth Foundation to replicate our program at four sites in North America. Speech-language pathologists and people with aphasia at these sites used our materials and gave us valuable feedback. We have recently achieved our ultimate goal of assisting others in starting aphasia book clubs — our Book Connection manual and materials can now be downloaded from the ACC Web site (www.aphasiacenter.org). We will be using proceeds to develop materials for additional books.

FORMING A BOOK CLUB

We start with a simple, one-page flyer that provides specifics about the book's title and author, as well as the day and time that the weekly discussion sessions will meet. We determine how many weeks it will take us to complete the selected book and calculate the fee for the class. Book Connection™ fees cover the cost of the speech-language pathologist's preparation and session time (about 2 to 3 hours a week when using already prepared materials), as well as the cost of the book and other materials that will be used. You can distribute flyers to stroke groups and local speech-language pathologists. Most of our groups accommodate five to 10 members.

READING RAMPS

In order to make the books accessible to a broad spectrum of people with different severities and types of aphasia, we use “reading ramps.” Reading ramps are modifications and strategies that make information accessible to people with aphasia. For example, we choose books that are available in an unabridged audiobook format so that participants can follow the print book word-for-word, if desired.

We have discovered that Talking Books, through the National Library for the Blind (www.nls.blind.org), is a great resource for free access to unabridged books on tape and tape players. However, qualifying for this service following a stroke may take special permission, so it’s important to contact your local Talking Books regional center to discuss the process.

We also choose books that have a relatively straight plot line. Plots that jump back and forth in time are more difficult to follow. And we look for large print books because many of our members have told us that they are easier to read.

Other reading ramps include chapter highlights and summaries, which support the book’s content by emphasizing key parts of the storyline while simplifying the vocabulary and grammar. Book club members use these summaries in a variety of ways.

Some review them prior to listening to the audiotapes. Others listen first and then use the summaries as a review. Some members choose to read the summaries without using the book or the audiotapes. And other members highlight selected parts of the summary to help them find items they want to talk about during the weekly discussions.

Weekly worksheets are another helpful reading ramp. These worksheets give participants the opportunity to make a personal connection to the story while providing reading and writing practice. The themes and questions from the worksheets also provide a springboard for discussion and review of the story.

We learned that we needed three levels of worksheets in order to meet the reading and writing abilities of all of our members. The content of all three is similar, but one requests multiple-choice answers, the second requests single-word, short-phrase, or even drawn answers, and the third requests sentence and paragraph answers.

Completion of worksheets is always optional — some members complete them regularly each week; others prefer not to.

TALKING ABOUT IT

The weekly discussion sessions are the most important part of the Book Connection program and the hands-down favorite of participants. These discussions promote an


exchange of ideas and thoughts that many individuals with aphasia tell us they don’t get the opportunity to have in their daily life. The discussion sessions work best when they are not a strict review of the book content or worksheets. Instead, discussion sessions are most engaging when they emphasize members’ reactions to chapter highlights and ideas, as well as any personal connections to the material.

Martha L., a longtime member of our Book Connection program, said of the weekly discussions, “I gain a lot from others...Group is wonderful...It’s dynamic... Everyone can operate at a certain level and feel success. Even if they can’t speak, each person has ideas and energy and brings it to the class... You can be challenged at any level.”



The weekly discussions promote an exchange of ideas and thoughts that many individuals with aphasia tell us they don’t get the opportunity to have in their daily life.

Susie A. agreed, adding, “I love being in the book club. When I had my stroke...I was really, really sad about not reading because I LOVE reading...The book club has really gotten me reading...I listen (to tapes) and then I go...we have questions we have to answer and we also talk about what we thought. It’s a great way to get together and say what we want to say and learn to read and write.” Our Book Connection experience has taught us that, regardless of the severity level of the aphasia, Holbrook Jackson was correct when he wrote, “The end of reading is not more books, but more life.”

For more information on aphasia, or to find an ASHA-certified speech-language pathologist in your area, call ASHA’s HELPLINE at 1-800-638-8255, e-mail ASHA at stroke@asha.org, or visit ASHA on the Web at www.asha.org. 

Increasingly, patients with aphasia participate in activities, such as book clubs, technology groups, and art and drama clubs. Such experiences help patients regain their confidence and social self-esteem, in addition to improving their communication skills. Stroke clubs, regional support groups formed by people who have had a stroke, are available in most major cities. These clubs can help a person and his or her family adjust to the life changes that accompany stroke and aphasia. Others involve activities that stimulate the mental representations of sounds, words, and sentences, making them easier to access and retrieve. Researchers are also exploring drug therapy as an experimental approach to treating aphasia. Aphasia can be extremely stressful for both the individual who had the stroke and their family and friends. Speech is such a significant part of human interaction, and it's something that most people take for granted. It's hard to be able to communicate if you've been dependent upon verbal communication and yours is suddenly impaired. Fortunately, some recovery from aphasia is possible, and there are still ways to effectively communicate, even with aphasia.

What is Aphasia? Aphasia occurs when there is damage to the brain—specifically, to the left half of the brain, which is the part that deal

The Book Connection's manual and curriculum materials provide "reading ramps" to help make books accessible to individuals with acquired reading impairments. These reading ramps include materials for content review of chapters in the book, worksheets to promote comprehension and personal connection to the story, and guidelines for facilitating book club discussions. The materials and manual are contained in computer files that are downloaded by purchasers. Although these materials were specifically developed to accommodate the communication challenges associated with aphasia, they may also be appropriate for other populations.

The Book Connection's Facilitator's Manual. Ellen Bernstein-Ellis, MA, CCC-SLP Roberta J. Elman, Ph.D., CCC-SLP, BC-ANCS.