**AAC**
Series

# Supporting Communication for Adults with Acute and Chronic Aphasia

edited by

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# Communication Support for Everyday Life Situations

Nina Simmons-Mackie and Julia M. King

Everyday life situations typically involve communication. Whether it is communication with oneself or with other people, the importance of successful communication cannot be underestimated. Communication is the essence of human life (United States Society for Augmentative and Alternative Communication, 2009). Each individual's essence or nature develops from daily interactions in the world. In fact, engaging in life situations (i.e., doing things), connecting with other people, and feeling optimistic and hopeful for the future are key components of "living successfully" with aphasia (Brown, Worrall, Davidson, & Howe, 2010; Grohn, Worrall, Simmons-Mackie, & Brown, 2012).

Daily communication experiences vary and are as unique as each individual. Everyday communication is often taken for granted until a barrier or challenge occurs. Everyone experiences barriers in everyday communication (e.g., an uncharged cell phone, forgetting the grocery list on the kitchen counter, difficulty hearing someone in a noisy room). However, for a person with aphasia there will be additional barriers and challenges that affect everyday communication because of the language impairment. Successful engagement in everyday situations by people with aphasia often requires communication supports that facilitate communication and participation. Supporting everyday communication is the focus of this chapter.

Throughout this book, the approach of supporting communication in general as well as during specific periods of rehabilitation has been discussed and illustrated. This approach advocates considering the person with aphasia as someone who has individual communication needs that can be supported in a variety of ways (e.g., changes in the environment, communication partner training, development of communication support tools, use of personally relevant therapy stimuli). Just as

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supporting communication is critical during intervention programs, planning for everyday communication situations must be considered from the onset of aphasia. This planning requires an understanding of the typical situations that people encounter in everyday life, as well as the unique or favored activities encountered by each individual with aphasia. Planning should lead to intervention focused on genuine, authentic communication that occurs in realistic settings. Traditional speech-language intervention has involved language or communication tasks that often are artificial or decontextualized (e.g., naming picture cards). If a person with aphasia is to realize improved participation in everyday communication situations, then intervention should involve a process of scaffolded (i.e., supported) learning focused on actual communication needs, appropriate tools, resources in the community, role playing, and authentic practice.

In general, people with aphasia want to engage in similar activities as adults without aphasia (Davidson, Worrall, & Hickson, 2003). However, some people with aphasia report that engaging in activities and starting new activities is difficult and that their lives tend to be restricted to routines such as daily chores (Nätturlund, 2010). Also, there are individual variations in the relative importance and relevance of particular activities. For example, one individual might find reading to be a significant aspect of leisure life, whereas another rarely reads for pleasure. In addition, activities are sometimes associated with specific groups of people. For example, a variety of child care activities are typical of parents or grandparents but are less typical of adults with no children. Relatedly, everyday activities and the manner in which they are carried out are sometimes culture-specific. For example, oral traditions and storytelling are favored methods of teaching by some aboriginal cultures, whereas Western Anglo cultures tend to favor more structured didactic learning activities. Thus, understanding everyday activities for an individual might require consideration of personally relevant activities, relatively generic activities, and/or population- or culture-specific activities (Worrall, McCooey, Davidson, Larkins, & Hickson, 2002).

## DEFINING EVERYDAY SITUATIONS

Everyday situations are those activities that people perform in the course of daily life, such as chatting on the phone with a friend, ordering at a café, reading the morning newspaper, or managing household finances. Everyday situations can be relatively specific tasks (e.g., making a grocery list) or major elements of life participation (e.g., being a mother). The World Health Organization International Classification of Functioning, Disability and Health (WHO ICF, 2001) classifies life situations into nine categories as follows:

- Communication (e.g., speaking, conversing, producing nonverbal messages)
- Interpersonal interactions and relationships (e.g., family, friends, strangers, intimacy)
- Major life areas (e.g., education, employment, managing finances)
- Learning and applying knowledge (e.g., learning to read, learning to use e-mail)
- General tasks and demands (e.g., performing required tasks)

- Mobility (e.g., walking, driving, using transportation, using one's hands to pick up things)

- Self-care (e.g., washing, dressing, eating, toileting)

- Domestic life (e.g., preparing meals, shopping, doing housework, assisting others)

- Community, social, and civic life (e.g., recreation, religion, political life)

This list of categories suggests the potentially huge variety of everyday situations in which people with aphasia and their families might need or wish to participate. Consider, for example, the category of community, social, and civic life; this category might include playing cards with friends, following a favored sports team, volunteering at the local food bank, reading a scripture passage at church, or analyzing the platform of a political candidate. Each of the life situation categories is considered in this chapter as it relates to supporting communication and participation for individuals with aphasia.

## FUNCTIONAL COMMUNICATION AND EVERYDAY SITUATIONS

Many, if not most, everyday situations require language and communication. The type of communication employed in everyday situations is often referred to as *functional communication*. For people with aphasia, communication support is an important consideration in facilitating functional communication and participation in everyday situations. Communication support resources and strategies will vary widely depending on the characteristics of the person with aphasia, the target situation or activity, and aspects of the environment.

## ASSESSING SUPPORT FOR EVERYDAY SITUATIONS

The characteristics of the person with aphasia, the target situation or activity, and aspects of the environment are traditionally considered during an assessment. In Chapter 6, a novel approach to assessment was presented by Hersh, Worrall, O'Halloran, Brown, Grohn, and Rodriguez. These authors recommended using a therapeutic assessment approach when assessing communication support for someone with aphasia. This approach is based on the principles of dynamic assessment, adult learning theory, and person–environment fit. Therapeutic assessment guides the process of determining which factors to consider when supporting communication. This applies to communicating in everyday situations as well as other communication activities. The framework in this chapter addresses therapeutic assessment by providing specific environmental and life categories to consider when discussing communication needs and supports with each individual with aphasia, as illustrated in Box 9.1.

## EVERYDAY SITUATIONS AND THE ENVIRONMENT

Aspects of the environment in which everyday situations occur will markedly impact the opportunities available and the participation level of the person with aphasia. The WHO ICF (2001) classified environmental factors that are likely to have an impact on participation as follows:

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## BOX 9.1

### Supporting Doris's Choice of Leisure Activities

Before arriving at their first appointment with the speech-language pathologist (SLP), Doris and her husband had completed a questionnaire that asked information about Doris's life, such as a list of her favorite activities prior to aphasia and favorite activities postonset. Later, as part of the Assessment for Living with Aphasia (ALA; Kagan et al., 2010), the SLP asked Doris whether she was doing as much as she wanted in the area of leisure activities. Doris pointed to *Definitely no* on the rating scale. Armed with information from the earlier questionnaire, the SLP was able to follow up on this question using supplemental support materials (not included in the ALA). For example, the clinician asked Doris what she would like to be doing in her free time. Doris's responses were supported by a set of pictures depicting items that had been identified as favored activities on the questionnaire. Doris pointed to a picture depicting scrapbooking and gave an emphatic thumbs up.

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- Products and technology (e.g., building design, electronic devices, wheelchairs)

- Natural environment and human-made changes to environment (e.g., lighting, sound, physical space)

- Support and relationships (e.g., family, friends, attendants, health care providers)

- Attitudes (e.g., individual attitudes, social norms)

- Services, systems, and policies (e.g., communication systems, legal system, health policies)

Using the WHO ICF as a framework, Howe, Worrall, and Hickson (2008) identified factors in the environment that affected the ability of people with aphasia to participate in everyday situations. For example, they found that modifications to products and technology could facilitate participation (e.g., modifying written information helps people with aphasia read; color-coded signage helps people with aphasia find their way around buildings). Conversely, products and technology can present barriers to the participation of people with aphasia. For example, phone trees and lack of standardized automated machines (e.g., credit cards, bank teller machines) hinder task management for people with aphasia. Similarly, background noise or visual distractions impede performance of everyday activities; thus, discussing one's mortgage with a bank officer at a desk in a busy bank lobby is typically distracting and difficult for someone with aphasia. Activities with time limits are also barriers to participation (e.g., cashing a check with a line of people waiting; asking a question of a busy pharmacy clerk). People with aphasia report that negative attitudes of others can affect their ability to perform tasks and reduce the likelihood of repeating the activity. Finally, policy barriers also inhibit participation of people with aphasia. For example, barriers might include having to complete a written form to report a crime or being required to perform a spoken phone interview to apply for financial assistance.

There are many environmental barriers to successful participation in everyday situations for people with aphasia. Environmental barriers have been addressed through the creation of aphasia-friendly documents (Rose, Worrall, Hickson, &

Hoffmann, 2012) and through training for businesses to become aphasia friendly (Polovoy, 2012; Snyder Center for Aphasia Life Enhancement, 2012). Rose et al. (2011) determined that the aphasia friendliness of written materials is related to how content is conveyed and how documents are designed. Aphasia-friendly documents include graphics and spaced information on the page and use color, large print, and clear wording. Appendix 2.1 in Chapter 2 contains specific guidelines for creating aphasia-friendly documents. Environmental barriers were also addressed by members of the Snyder Center for Aphasia Life Enhancement, who developed aphasia-friendly communication tools; provided in-service training about aphasia; and assessed businesses for signage, accessibility, and employee knowledge and skills when interacting with people with aphasia. As a result of this work, seven businesses in Baltimore, Maryland, have eliminated environmental barriers and are now considered aphasia friendly (Polovoy, 2012). However, these environmental supports are not available for most people with aphasia.

Environmental accommodations exist for people with visual, hearing, and physical disabilities; however, accommodations are rare or nonexistent for language impairments. Imagine an aphasia-friendly world in which all environmental factors (i.e., products and technology, natural environment and human-made changes to the environment, support and relationships, attitudes, services, systems and policies) were considered for people with language impairments, such as aphasia. An aphasia-friendly world might be more reachable if people who understand aphasia work together to increase awareness and educate the public on ways to support language and communication. One specific way to make the environment more aphasia friendly is to have speech-language pathologists (SLPs) consider environmental supports when they collaborate with people with aphasia to support everyday communication. Examples of aphasia-friendly environmental accommodations are listed in Table 9.1.

Identification of environmental barriers and implementation of modifications are forms of communication support that help people with aphasia participate in everyday situations. Environmental modification can be undertaken with the guidance of professionals, such as SLPs, but people with aphasia and their loved ones can also problem-solve ways to circumvent environmental barriers (see Box 9.2). In addition, environmental modifications that support the participation of people with aphasia can be undertaken by businesses, institutions, communities, and government.

**Table 9.1.** Aphasia-friendly environmental accommodations

| Environmental factors | Aphasia-friendly examples |
| --- | --- |
| Products and technology | Phone trees offer different rates of presentation.<br>Operator assistance is offered early in a phone tree. |
| Natural environment and human-made changes to environment | Businesses offer separate rooms for consultations/meetings. |
| Support and relationships | Other people are willing and knowledgeable in use of supports when communicating with the person with aphasia. |
| Attitudes | People embrace different methods of communication. |
| Services, systems, and policies | Emergency personnel are required to learn how to support communication for people with aphasia. |

*Source:* World Health Organization (2001).

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### BOX 9.2

### Kinsey's Participation in a Cooking Club

Kinsey, a 58-year-old woman with moderately severe aphasia, lived at home with her husband. Before the onset of aphasia, one of Kinsey's typical pastimes was cooking family meals. She had enjoyed trying out new recipes and making meals for her husband and adult children. She also enjoyed trading recipes with friends and preparing dishes for various social gatherings. After the onset of aphasia, Kinsey found it difficult to read recipes, make up grocery lists, and follow printed instructions. Kinsey lacked confidence in her cooking ability and tended to avoid trying new recipes.

Recognizing the impact of aphasia on this important everyday activity, Kinsey's husband consulted a speech-language pathologist, who recommended that they create a "cooking club" composed of several adult family members and friends. The group (including Kinsey) would meet to talk about recipes and identify recipes to target for the following week. A goal of the cooking club was to identify methods to help negotiate the everyday task of preparing meals while also providing Kinsey with a fun social outlet. The group talked about recipe ideas, searched online recipe sites, and brainstormed methods of making recipes or preparation more aphasia-friendly. For example, the group found that larger print, more blank space on pages, and use of a routine structure for recipes helped Kinsey follow recipes. After meetings, volunteers would reformat specific target recipes to be more aphasia friendly and send Kinsey the reformatted recipes along with matching printed grocery/ingredient checklists.

Through modification of the recipes (a change in the external environment), Kinsey's ability to negotiate meal planning and implement new recipes improved, and her confidence increased significantly. Over time, Kinsey learned to reformat recipes herself, and she slowly gained more independence.

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## SUPPORTING EVERYDAY SITUATIONS

Implementing supports for everyday circumstances will depend on each person's life situation. The life situation categories from the WHO ICF provide a framework for discussion to begin the process of supporting participation in everyday situations. The following categories illustrate the importance of everyday communication as well as considerations for supporting participation in these situations.

### Communication

The WHO ICF category Communication pervades most of the other categories. For example, communication is required to manage interpersonal relationships and engage in social life. Communication is often required to perform tasks associated with domestic life, such as preparing grocery lists or making appointments. Thus, attention to communication in everyday situations will be considered throughout this chapter, with the exception of conversation, which is considered in the next section.

*Conversation*    One of the most pervasive and important everyday communication activities is conversation. In fact, conversation has been considered the pre-

eminent form of communication in Western cultures and has been reported to be the most frequent communication activity in which older people engage (Davidson et al., 2003). Conversation refers to the "authentic, usually spontaneous, communication associated with social interaction—the everyday, ordinary talk that serves dual goals of exchanging messages and fulfilling social needs" (Simmons-Mackie, 2000, p. 171). Consider a typical day: Most people will engage in numerous conversations—some will be brief and superficial, whereas others will be protracted and multilayered. These interactions not only allow a person to connect with others and take care of business but also provide a mirror of how one is viewed by others. Conversation also provides an outlet for managing emotions and problem solving. Thus, conversation is crucial to managing social relationships, to maintaining mental health, and to negotiating identity and self-esteem.

Conversations typically involve a variety of speech acts (e.g., commenting, questioning, making assertions, promising) and genres (e.g., storytelling, joking, relating a list). Conversation involves the dual goals of exchanging information (i.e., transactional communication) and engaging socially (i.e., interaction; Simmons-Mackie, 1998; Simmons-Mackie & Damico, 1995). Although the goal of exchanging information is fairly well recognized, the role of conversation in managing social connections is sometimes overlooked. For example, people use communication to affiliate with others, to sustain intimacy, to maintain autonomy, or to distance themselves.

Aphasia can have a significant impact on the ability to engage in meaningful and satisfying conversations. However, research has suggested that the negative impact of aphasia on conversation can be ameliorated, in part, with communication supports (e.g., Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001).

*Communication Supports for Conversation*   *Multimodal* or *total communication* refers to the use of a variety of modes and strategies to augment natural speech (see Tables 9.2 and 9.3 for examples). Use of multimodal communication by a person with aphasia can facilitate the transmission of messages and the management of the social interaction during conversation. For example, a pointing gesture might transmit a message in the face of inefficient spoken language: "This one (pointing to wedding ring to indicate wife) is sick." Similarly, a pointing gesture might help to manage the interaction when the person with aphasia points to the listener to indicate a desired turn shift or raises a hand to indicate the desire to hold a turn while searching for a word.

Training of multimodal communication takes a variety of forms. One approach to direct training, the Multimodality Communication Training Program (MCTP; Purdy & Dietz, 2010), involves intensive practice of multimodal communication, including switching among modalities. The program focuses on directly training various modes of message transmission:

> The clinician presents a picture and the person with aphasia states the name, describes it, writes the name, gestures the function, draws a picture, and references the concept in a low-tech AAC communication book, thus switching among modalities for a single item. After a response is elicited in each modality, a new picture is introduced. (Purdy and Dietz, 2010, p. 75)

Treatment proceeds in a hierarchy from maximum clinician input (e.g., client imitates clinician models) to fading of modeling and then to independent use. The simultaneous focus on multiple modes seems to overcome failure to generalize to everyday communication. The authors suggested that patients often learn to point

Table 9.2.    Examples of multimodality strategies for transmitting information

Speech
• Natural spoken communication (when possible)
• Using related words or circumlocution to get an idea across
• Supplementing natural speech with vocalizations (e.g., imitation of barking dog)
• Using voice inflection to communicate an idea (e.g., the word *baby* produced with rising inflection to ask whether the listener's wife has had her baby)

Facial expression

Gestures
• Deictic gestures (e.g., pointing to an object, person, direction, written word)
• Symbolic gestures (e.g., gesture for *eating*, holding up two fingers to indicate 2)
• Pantomime (e.g., acting out having one's hair cut)

Writing
• Writing clues for the listener (e.g., writing first letter[s] of a word one can't think of)
• Written key words

Drawing

Graphic media
• Pictographs, drawings, icons
• Photographs: personal and generic; hard copy or digital
• Objects (maps, newspapers, objects in the environment)
• Communication books or boards
• Rating scales (e.g., pictographic pain-rating scales)

Electronic technology
• Applications for smartphone, tablet computer
• Speech-generating device

(e.g., to pictures in a communication book, objects), write, draw, or gesture in structured situations but fail to use these skills in natural communication. This failure of traditional methods of teaching multimodal communication occurs because the skills are coded as a separate system, and clients retain a tendency to revert to highly ingrained verbal modes of expression when faced with spontaneous communication. By contrast, MCTP involves simultaneous attention to multiple modes and integrates these modalities into linguistic processing.

Table 9.3.    Examples of multimodality strategies for managing the interaction

Engagement strategies—strategies that help sustain interaction
• Affiliatives—help sustain interaction (e.g., smiling, looking interested)
• Back channels—comments that indicate interest or understanding (*mhm, right, oh yea, wow*)
• Gaze—indicating interest with eye direction
• Body language (e.g., leaning toward speaker)

Disengagement strategies—strategies that help discontinue interaction
• Gaze aversion
• Body language (e.g., shifting body away from speaker)

Turn allocation
• Gestures to shift turn to another (e.g., hand extended to a listener)
• Placeholders to hold a turn while trying to get a word (e.g., hold up hand in *Stop* gesture)

Whereas MCTP is a relatively didactic and direct approach to training, other methods of multimodal communication training include more implicit learning approaches involving modeling and reinforcement of strategy use during interactive activities. For example, Promoting Aphasics' Communicative Effectiveness (PACE) is an approach to aphasia therapy that draws from principles of natural interaction (Davis & Wilcox, 1985). PACE employs barrier tasks in which the clinician and client take turns choosing a stimulus item (e.g., picture card, written instruction) and attempting to communicate the contents/meaning of the item to the other person (who does not see the item). To promote the use of multimodal communication, the clinician models target strategies during his or her turn and also encourages the client to use strategies (e.g., "I don't understand; can you show me something with your hand? Can you write it for me?"). The situated use of multimodal strategies helps clients practice in an interactive context and experience success with multiple modes. An even more implicit approach occurs in group conversation therapy (e.g., Elman, 2007; Simmons-Mackie, Elman, Holland, & Damico, 2007). Although a range of modalities can be modeled during group treatment, clinicians reinforce those that are most successful for each individual. In-depth analysis of several group conversation therapy sessions revealed that multimodal communication strategies were used throughout sessions by both clinicians and clients:

> When members [with aphasia] encountered trouble communicating, clinicians tended to model alternative modes and strategies or directly suggest particular strategies ("Is it something you can draw?"). Thus, multimodal communication was an integral part of conversations and activities, and was employed by clinicians as well as group members. (Simmons-Mackie et al., 2007, p. 11)

Group conversation therapy is a highly authentic approach to multimodality training because it incorporates training into the natural context of conversation (the target activity).

Photographs, drawings, or remnants are a common source of support used during conversations. Visual referents can serve as topic starters as well as a means to convey specific content during conversation. Photographs of children and grandchildren are common visual referents used to talk about families. Family photographs are often readily available in hospital rooms, or they might be found in people's wallets or purses. The use of photographs or visual images to engage in conversation may require explicit training for a person with aphasia as well as his or her communication partners. Using the photograph to provide context for a conversation instead of eliciting a single comment is not intuitive to many people. Writing the name, birthday, age, and where the person lives on the back of the photograph or as a caption in an album can add to the richness of the communication support for conversation. Another example of a visual referent is an aphasia identification card (e.g., National Aphasia Association, http://www.aphasia.org). This card serves as a conversation support tool that can educate others about aphasia and provide strategies and tips about how the person with aphasia communicates.

Researchers have documented the benefits of visual supports in conversation. Garrett and Huth (2002) found that the presence of visual supports increased the number of interactions and initiations during conversation and also improved the success of interactions for adults with aphasia. In addition to individual photographs or graphic images and items, visual scenes can support conversation.

Visual scenes represented on a paper display or as images in an electronic device are referred to as *visual scene displays* (VSDs). VSDs portray situations, places, or experiences that show relationships and interactions with people (Beukelman, Fager, Ball, & Dietz, 2007; Hux, Buechter, Wallace, & Weissling, 2010). VSDs serve as a shared communication space that a person with aphasia and a communication partner can use in conversation to coconstruct messages (Hux et al., 2010). VSDs are different from individual photos. For example, a photograph of a family carrying a cooler next to a camper is an example of VSD. A photograph of the family taken in a photographer's studio would illustrate the members of the family (and, perhaps, relationships), but it would not convey the story of the event or tradition related to camping (see Figure 9.1). It is important to consider how the visual image represents relationships and interactions when choosing photographs and pictures and the intended reason for using the visual scene (e.g., to tell a story) in conversation.

Most people have conversational styles and favored methods of engaging with others. For example, one person might be known for quick witticisms during the give-and-take of conversation, whereas another will tend to relate events in amusing monologues, and a third person will tend to quote facts. People with aphasia likely have preonset conversational styles; often, a person's aphasia has an impact on his or her favored style. For example, Davidson and colleagues (2003) found that storytelling was an important aspect of conversation among older people. Communication supports can be programmed to support specific communication genres. For example, a variety of communication supports can allow a person with aphasia to relate a story to others. An electronic device can be used to prerecord a story; the story can be played for others by the person with aphasia, who can use body language and gestures to bring the story to life, stop the recording to make comments, or allow others to insert comments or expand. Alternatively, a pre-prepared script or key word/phrase list might serve as a self-cue during spoken storytelling; the person with aphasia might prepare the script using word processing with spell-check and word prediction to aid writing. Other people, such as family members and friends, can support storytelling by scaffolding and seamlessly expanding on the person with aphasia's utterances, as described in Box 9.3.



**Figure 9.1.**    Visual scene display versus photograph.