

National Aphasia Association (NAA) Aphasia Bill of Rights

Over one million people in the United States have aphasia, a communication disorder that is the result of stroke or brain injury. Yet, many of these people leave the health care system without even knowing that their difficulty communicating has a name - aphasia. "In addition, the majority are not told about the resources available in their own communities that could help them," notes Martha Taylor Sarno, MA, MD (hon), founder and president emeritus of National Aphasia Association (NAA).

In response, the NAA's Board of Directors has passed the Aphasia Bill of Rights (below) to spell out the information and services that people with aphasia need to move forward with their lives. The NAA is calling on health care providers, facilities, and accrediting bodies to incorporate these rights in their treatment of people with aphasia.

If you have any questions about the Bill of Rights, please contact Joan Peters, Executive Director, National Aphasia Association, 7 Dey St. Suite 600, New York, NY 10007, tel. 212-267-2814 email: peters@aphasia.org.

The NAA's mission is to reconnect people with aphasia with the community by educating the public, encouraging the use of local resources, and advocating on behalf of those who are left, literally, without a voice. The NAA provides information through its publications, including *The Aphasia Handbook: A Guide for Stroke and Brain Injury Survivors and their Families*, and its website www.aphasia.org. It is the only national organization that is dedicated to raising aphasia awareness among the general public.

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WHEREAS:

- aphasia is a condition, usually acquired as a result of stroke or other brain injury, which impairs the ability to use or comprehend words, but does not affect intelligence, and
- as a result of their difficulty communicating, people with aphasia may experience great isolation and frustration in their daily lives, which is often made worse by the lack of information that they receive about their condition, and
- many people are never even told that their difficulty communicating has a name - "aphasia" - and the majority leave the health care system without referrals to resources in their own communities, and
- people with aphasia must be accorded the same rights as other patients to full and adequate medical treatment, insurance coverage, and research regarding their condition, and
- people with aphasia have the same fundamental rights as other members of society, including the right to the pursuit of happiness and a full and positive quality of life,

NOW, THEREFORE on September 26, 2005 the Executive Board of the National Aphasia Association (NAA) votes unanimously to approve the following Bill of Rights:

People with aphasia have the right to:

1. Be told, as soon as it is determined, preferably by a qualified speech-language pathologist (SLP), both orally and in writing, that they have "aphasia" and given an explanation of the meaning of aphasia.
2. Be provided, upon release from the hospital, with written documentation that "aphasia" is part of their diagnosis.
3. Be told, both orally and in writing, that there are local resources available to them, including Aphasia Community Groups in their areas, as well as national organizations such as the National Aphasia Association (NAA).
4. Have access to outpatient therapy to the extent deemed appropriate by a qualified speech-language pathologist (SLP).
5. Give their informed consent in any research project in which they are participating.
6. Demand that accrediting health care agencies and health care facilities establish requirements for and competency in caring for people with aphasia