

The Inside Story

Inspirational accounts from individuals who live with communication disorders

By Barbara Meissner Fishbein



As health care professionals, it is sometimes easy to get lost in the day-to-day business of assessing and treating patients/clients with communication disorders. Members see their patients/clients, ensure that their documentation meets CASLPO standards, and try to stay current in their fields of practice by reading professional journals and attending courses. Members rise to the challenges presented by their patients/clients, their work environments, and the seemingly ever-decreasing resources needed to treat an ever-increasing number of patients/clients with complex communication disorders. At the end of the day, many CASLPO members must wind down and regroup in order to have the strength to do it all again the next day. Sometimes in the course of trying to do the best they can do, it can be hard to remember why they wanted to be an audiologist or speech-language pathologist. Yet when members start to question *their raison d'être*, the perspective of their patients/clients can be enough to reawaken their passion for their profession.

When members choose to work with their patients/clients (and those with whom they share their lives) to articulate their stories of communication impairment and rehabil-

itative success, a powerful message begins to emerge. Patients/clients and those around them provide personal insights into the hardship and challenge a communication disorder can create. Patients/clients are also the best judges of how effective our members can be at providing them with the resources that they need to face the adversity a communication disorder can bring. When CASLPO members listen to the families, caregivers, and others of importance in the patient/client's circle, they learn that communication disorders can have a profound impact on interaction and all aspects of life. These messages become powerful tools in rekindling professional motivation and raising awareness of the professions. Many CASLPO members know this only too well. They understand that this approach can be used to educate their communities and highlight the important work that they do.

An example of one such group of members are the speech-language pathologists at Bridgepoint Health, an integrated health care organization in Toronto that specializes in rehabilitation and complex continuing care services within the institution and in the community. The concept for a public panel discussing the recovery process and

communication disorders arose out of the insight of one perceptive spouse. The wife of one of the speech-language pathology patients/clients began reflecting on her husband's rehabilitation and how much she had learned from the experience. As she did so, she realized that she had acquired a considerable body of knowledge about stroke, aphasia, rehabilitation, and the impact of all this on patients/clients and their families. It occurred to her that this was knowledge that would have been useful to her at a much earlier stage in her husband's recovery. She wanted the opportunity to share what she now knows with others who are facing similar challenges, so she asked her husband's speech-language pathologist, Aviva Joel, for assistance.

Joel considered this request and approached her colleagues, Elizabeth Hanna, speech-language pathologist, and Robin Snyder, communication disorders assistant. Together they decided that not only was this a message worth sharing, but that there were others with similar stories to tell. They found another four family members of their patients/clients who were willing to talk about their experiences and share what they had learned.

On May 17, 2006, they sponsored a

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family education session titled "The Ripple Effect: Living with Communication Impairments, Learning from Those Who Do." Their panel consisted of an adult child speaking about her experience with her mother, and two other spouses in addition to the one who sparked the idea. Another spouse who could not attend provided her remarks on videotape. An effort was made to publicize the event, which was well attended by speech-language pathologists and other health professionals, students, individuals with communication disorders, others who know someone with a communication disorder, and members of the community.

The panel members spoke eloquently about the devastating effects the communication disorders had on their loved ones, the frustrations of getting the appropriate services, and the lack of understanding that they had encountered from friends and the community at large. One panelist spoke about how hard it was when friends tended to drop off. These were described as the "call me when you are better" friends, referring to people who were uncomfortable interacting with those with communication impairments. Others described feeling lonely and abandoned. They admitted to feeling overwhelmed by their emotions and those of their family members and the demands of coping with a communication impairment. As one spouse put it, "We had all these plans for our retirement, and now they had to stop." All the panellists agreed that their communicatively impaired family members needed an advocate to ensure that they were treated appropriately and with dignity and respect.

Yet, in the face of these considerable challenges, the panellists described their profound admiration and

respect for their family members. Their ability to communicate when words failed, their perseverance and determination to make the most of therapy, and their single-minded effort to realize their potential and get on with their lives were awe inspiring. A daughter described her mother as putting her heart and soul into therapy. A wife described the uplifting experience of watching her once-speechless husband resume singing in church. A husband spoke with intense pride of the communicative skills of his wife whose personality broke through her difficulties using language. All panellists had many suggestions for improvements in the rehabilitation services that they had received, but they had nothing but praise and appreciation for the speech-language pathologists whom they had encountered in the course of their rehabilitation journey. They referred to this journey as a "long and bumpy ride," one that is life altering and relentless but one that can be conquered with support.

The Aphasia Institute is dedicated to reducing language barriers to full-life participation. The programs that they run through the Pat Arato Aphasia Centre are administered in partnership with communicatively impaired individuals and their families. They strive to improve the quality of life and well-being of their members. They also endeavour to change society by promoting communicative access for those who require assistance and are committed to inspiring others to do the same.

The idea of having members of the centre and families participate in a public presentation was the brainchild of Rochelle Cohen-Schneider, speech-language pathologist, who is



the director of Clinical and Educational Services at the Aphasia Institute. The aim was to create a forum to promote the work done by the institute and highlight how participants in their programs create meaningful lives while living with a communication impairment. A committee was struck with representation from the board, program participants, staff, and volunteers to create an event designed to provide hope, inspiration, and practical information about living with a communication disorder. Cohen-Schneider worked with the committee assisted by Esti Cohen and Ashley Sankowski, two University of Toronto speech-language pathology students, as well as her speech-language pathologist colleagues Aura Kagan, Lorraine Podolsky, and Susan Watt.

All the planning of the committee took shape on June 8, 2006, when "Discovering a New Life: An Aphasia Awareness Day Event" was held. Two separate presentations were offered, one during the day primarily for individuals with communication disorders and their families, and one in the evening for health care professionals. Both sessions were well attended. The organizers were especially pleased that one hospital arranged transportation for many of their patients/clients to attend. The evening session began with Toronto city council member Raymond Cho presenting a proclamation on behalf of Mayor David Miller declaring the first week in June as Aphasia Awareness Week in the city. The session was enhanced by a compelling talk given by Toronto Rehabilitation Institute neuropsychiatrist Dr. Abraham Snaiderman. He dramatically described how effective communication is possible without speech or language and underscored the need to support those who are challenged by communication impairments.

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However, the highlight of the sessions was the panel discussion. The panellists consisted of two couples of which one spouse was a member of the Pat Arato Aphasia Centre. They were interviewed by another individual who was also a centre member. The panellists who were facing communication challenges spoke about the initial devastation of the precipitating event that led to their communication impairment and the depression that followed as the individuals and their families mourned the loss of their communication skills. They found they were unable to pursue many of the activities that they had in the past and reported losing hope that they would resume any of them. Their partners talked about the pain of watching their loved ones cope with the significant changes in their lives and the feelings of helplessness as they tried to provide comfort and support.

But much like their Bridgepoint colleagues, these individuals spoke about the powerful restorative effect of rehabilitation on their outlook, their ability to cope, and their ability to regain skills and pursue interests that they thought were lost to them. Their families spoke with the same profound admiration and respect that was expressed at the Bridgepoint panel for the strength, stamina, and courage demonstrated by the individuals as they learned to cope with their communication deficits and grow beyond them. One husband spoke of his delight to see his wife return to an *active lifestyle that now consisted of some new activities such as participating in the Toastmasters public speaking club at the Aphasia Centre.* He also didn't mind that she had resumed some activities she previously enjoyed such as shopping in favourite stores! One wife spoke of how she came to appreciate the resilience of the

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human spirit watching her husband recover and regain his motivation and interest in his many hobbies. She saw qualities in her husband, whom she thought that she knew well, that she had not realized were there. She described the transformation as miraculous. Her husband on the other hand attributed his success to perseverance and hard work. He summed up his advice to others by telling the old joke, "How do you get to Carnegie Hall? Practice, practice, practice!"

These panellists spoke at length of the challenges they faced maintaining their independence while coping with their communication impairment. They spoke about the frustration of dealing with individuals who responded to their difficulties with rudeness or by being abrupt. They did say that most people, once they understood, were helpful and supportive. They suggested that an effective strategy was to declare their communication deficit before trying to communicate, thus alerting their listener that extra time and patience may be required. One panellist offered that *this strategy was particularly useful when trying to avoid annoying telemarketers!*

Without fail, panellists consistently commended the speech-language pathologists they had worked with and the Aphasia Institute for providing them with support and guidance. They unanimously agreed that this was an essential

component of their recovery. The speech-language pathologists in turn expressed their gratitude to the panellists for the information that they provided and the opportunity to learn from their experiences by making them public.

The panels presented by Bridgepoint Health and the Aphasia Institute presented stories from the perspective of people living with communication disorders from both the viewpoints of the individuals and their families. The CASLPO members who listened and supported these expressions were demonstrating patient/client-centred care at its finest. But these speech-language pathologists did not stop there. They realized that these stories need to be heard by others in similar circumstances. They understood the powerful messages that need to be conveyed by those who have lived through the experiences. They appreciated that these individuals could function as skilled ambassadors for the profession. That their patients/clients were inspired is a testament to their skill. That they inspired their colleagues is perhaps an unanticipated by-product. That they were inspired is an obvious truth.

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