

LOUD 'N CLEAR

The Newsletter of Speaking Differently

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APHASIA IN HUNGARY

by Claudine Goller

What help is available in Hungary for people who are aphasic, or have difficulty speaking clearly? In a word, nothing. Nothing, that is, until almost four years ago, when a foundation and club to help people who have suffered strokes and/or aphasia were established in a small city called Zahony, in the north-eastern part of Hungary. Zahony is on the Ukrainian border, over 300 km from the capital city of Budapest.

Who established this foundation and club, and why? Claudine Goller is a retired educator who lives in Toronto with her Hungarian-born husband Steve. Steve's niece Erzso lives in Zahony with her husband Zoli and their two children. In 1998, Zoli, 37 years old, suffered a stroke with complete aphasia and paralysis on the right side. After two months spent in three different hospitals, Zoli was sent home, unable to speak, read, write, or even understand what was said to him. He had received help from speech therapists and physiotherapists, but was still not able to communicate except by his facial expressions and some gestures and noises. Fortunately, he was able to walk, although he dragged his right foot, but he was not able to use his right hand.

Claudine and Steve knew that the situation was desperate for Zoli and Erzso, as there was absolutely no more help available to them. Erzso had been told to take up the carpets – so Zoli wouldn't trip – and that was it!

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WHAT IS APHASIA?

Individuals with aphasia experience difficulty in processing and/or using symbols. Symbols comprise much more than just language itself (eg. music notes, written words, speech sounds, sign language, colours, road signs...), and it cannot be said that individuals with aphasia completely lose the meanings of these various symbols. Rather, the associated meanings are simply misplaced, resulting in retrieval and manipulation problems. The most common cause of aphasia is a stroke, and the more severe the stroke, the greater the ensuing brain damage. Since most people's language control centres are located in the left hemisphere of the brain, it follows that damage to this side is more likely to cause deficits in oral and written expression and comprehension.



Above: a collage of works from SD's November art show featuring paintings by people with Aphasia and SD President Anne Abbott (top right).

POETRY

My Plea

There's something on my lips that nobody can see.
Please take it off,
Take it off and let me talk
This is my plea.

Let me talk without gestures,
But with my voice
This is my choice.

Words are so meaningful,
So moving,
So beautiful.

Remove this horrible thing,
Let me speak,
And like a bird – sing.

Let me move you with love in the tone of my speech,
The fear – the hostility,
Oh to speak!
Think of the possibility.

There's Something on my lips that nobody can see.
Please take it off,
Take it off and let me talk,
This is my plea.

By Anne K. Abbott

Poets and Poems!

Last issue we put out a call for poetry and this issue we've got it! Please keep your submissions coming in and Loud 'N Clear will feature a new poem and poet in each issue. This month's poet needs no introduction to Loud & Clear readers, as she is none other than SD president Anne Abbott, also featured in this issue's editorial. All submissions related directly or indirectly to AAC specifically or communication generally will be considered. If you want to be heard, Loud 'N Clear is the best way for you to get the word out – to other members nationally and to the world via the web! Email us at speakingdifferently@gmail.com or snail mail us at our mailing address.

The Aphasia Issue

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Aphasia in Hungary

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Claudine and Steve, after doing a great deal of research on strokes, aphasia, and what was available in Toronto, invited Zoli and Erzso to come to Toronto to try to get some help. And they accepted, although it meant leaving their two teen-agers with Erzso's mother.

At first, the plan was for them to stay for three months. During that time, Claudine found a Hungarian-speaking speech therapist who was able to help with some advice, although she had not worked previously with aphasics; she also found a physiotherapist who was excited to have the opportunity to work with someone like Zoli. And there was so much improvement, that Claudine and Steve invited Zoli and Erzso to stay longer, and even brought the children to Canada to visit their parents for Christmas.

Zoli and Erzso went back to Hungary after six months. But Claudine goes at least once a year to work with him, and Zoli has been coming to Canada every summer. Zoli wanted very much to regain his previous communication skills, and sometimes he and Claudine put in twelve-hour days. Eventually, he did learn to speak, read, and write – not perfectly, and only haltingly, but even that was a major accomplishment for him.

Claudine was thrilled to see how much Zoli improved, and because she had seen how much good is done by people at the Aphasia Institute in Toronto, and because of her experience with volunteer groups here in Canada, she suggested to Erzso and Zoli that they, with her help, try to begin a little club at home for people like Zoli. They did not even want to discuss it at first, because there was little or no history of volunteerism in Hungary, and because self-help groups were unheard-of at that time.

Claudine continued to talk with Zoli and Erzso about the difference they could make in the lives of others. They knew of several people living right there in Zahony who were aphasic; why not try to help them with the knowledge they had gained through their own experiences?

Although Erzso said that no one would want to listen to her because she did not have a university degree, Claudine finally convinced her and Zoli to try. Claudine told her friends in Toronto about what she wanted to do, and many contributed money so they would have something with which they could start a club.

Claudine again went to Hungary, and she and Erzso spoke to the family doctors, one of whom suggested they see a lawyer in another city. He made an appointment for them to meet with the lawyer, who said they should set up a foundation as well as the club. He was willing to help with the paper work.

It took four months for the paper work to be completed; before long, Claudine and Erzso realized that it was fortunate indeed that Claudine had brought money from Canada, because they had to set up two bank accounts, one with Canadian money, and one with Hungarian money.

Again Claudine went home, and this time, before she went back to Hungary, Erzso found a place to have the club meet – the mayor of Zahony was pleased with the idea of having a club for people who had suffered strokes and/or aphasia, and arranged for them to use a room in an old kindergarten building which was already being used by a group of seniors. They would

use the room on Mondays, from 10:00 a.m. to 1:00 p.m.

In the meantime, Claudine had been busy buying games and craft items, and anything and everything she thought might be useful in working with aphasics and stroke victims, and she got permission from Malev Hungarian Airlines to take some extra luggage containing materials for the club. So off she went again, this time, prepared to start the club after she arrived.

She and Erzso advertised by putting up posters around Zahony, although most of them were torn down right away. The doctors allowed them to put posters in their waiting rooms, and they also received permission to put posters in the entrances of the churches.

And they talked about the venture to everyone! But on the first day, it seemed that no one would come, although several people had called about the club. Erzso, Zoli, and Claudine had prepared, but for the first couple of hours, no one came - until two young women arrived, looking for help. The younger woman had recently given birth to a daughter; the doctors said the baby had suffered a stroke during birth, and they told the family that nothing could be done to help her. All Erzso and Claudine could do was to offer encouragement to the young woman and her sister. They must not believe that nothing could be done to help the baby. They must try to treat the baby the same way they would a healthy baby. They must never give up hope. They must love her and always be there for her, they said.

Erzso, Zoli, and Claudine went home just before one o'clock. No one else had come. No one else would come, Zoli said. But they went back the next Monday, and set everything up again, and that time, someone came! A woman who suffered from aphasia but could speak haltingly arrived a little after ten o'clock! How happy Erzso, Zoli, and Claudine were, and how happy the woman was to have found this meeting place for people like herself.

And since then, they have not looked back. Several more people arrived, and now they have a club that meets weekly, except for some weeks in the summer. Most of the people are male, but two are female. The wives of two of the men usually go with their hus-

bands; because of their physical situation, they require more assistance.

Fortunately, because Claudine cannot stay in Hungary, Erzso was able to enlist the assistance of a friend, a retired kindergarten teacher, who usually helps. As everything is done on a volunteer basis, it seems odd to many Hungarians, who probably wonder what they hope to gain from this. And the people who run the club have gained a great deal from it – a feeling of satisfaction, knowing that they have been able to help a few people who otherwise would not have a place to go to relax with friends, to do some exercises, to play some games, to learn to communicate with others. A great deal of learning takes place during those three hours each week.

And there is an even greater feeling of satisfaction for Erzso, who has been told by the wives of the two men who are in the worst physical condition that they are sure that had they known Erzso when their husbands first suffered their strokes and became aphasic, they would be able to do and say much more than they are presently able to do and say. Of course, one man had his stroke 18 years ago, at 43 years of age, and the other, 8 years ago, when he was 68 years old. Erzso has taught them all a great deal. And why? Because she wanted to learn all she could about strokes and aphasia, because she wanted so desperately to help her husband, and later, because she was willing to give of herself to help others who were in a similar situation.

The club continues to meet on Mondays. Every December they put on a bazaar, and it takes them several months to prepare for it. Relatives and friends make craft items and Christmas decorations, and some of them bake, many people help, and they bring others into the club to see what they are doing. They use the money they make to go to the theatre and a restaurant, where normally none of them would ever go.

Presently, they are working on presenting a play which Claudine wrote. The English title is 'Don't Let Them Suffer Alone!' Claudine had the play translated into Hungarian, and the club members are very excited about this venture. The first performance will be for relatives and friends; after that, who knows? Claudine hopes that the group will be invited to perform in hospitals, for medical personnel, patients, and their families, and even in schools, to help to educate young people about strokes and aphasia. The need is great.

Communicating With Adults With Aphasia

- **Don't talk down to the person.**
- **Minimize or eliminate background noises.**
- **Get person's attention before communicating.**
- **Acknowledge all attempts to speak.**
- **Avoid insisting that all words be produced correctly.**
- **Encourage use of all modes of communication (writing, gestures, yes/no, choices, etc).**
- **Give time to talk and respond.**
- **Keep your communication simple, but adult.**
- **Keep voice at a normal volume level, and emphasize key words.**
- **Speak slowly.**
- **Continue normal home activities (i.e. family dinners, company, going out, etc).**
- **Don't shield from friends and family.**
- **Include them in family decisions, but don't burden them with day to day details.**

Information supplied by



REHABILITATION, COMPLEX CONTINUING AND LONG TERM CARE

I N D E P E N D E N C E

Independence. What a wonderful word, what a wonderful ideal! It is what most of us dream of and strive for. And yet, who of us can say that we are truly independent? Who indeed!

For people with disabilities, independence can be as elusive as the Holy Grail. Obstacles are constantly being thrown in our path and we have to try to manoeuvre around them as best as possible. You want a new wheelchair or assistive device? Go find an occupational therapist and vendor, wade through a sea of funding red tape, and then sit back and wait for six months for your product to arrive. You want enough money to live on? ODSP will generously give you \$700.00 per month. And, if you dare to try to supplement your income or attempt to get off ODSP by starting your own business, a percentage of your already tiny pension is taken away.

And then there's attendant care. Great idea in theory. However, in practice ... well, that's another thing.

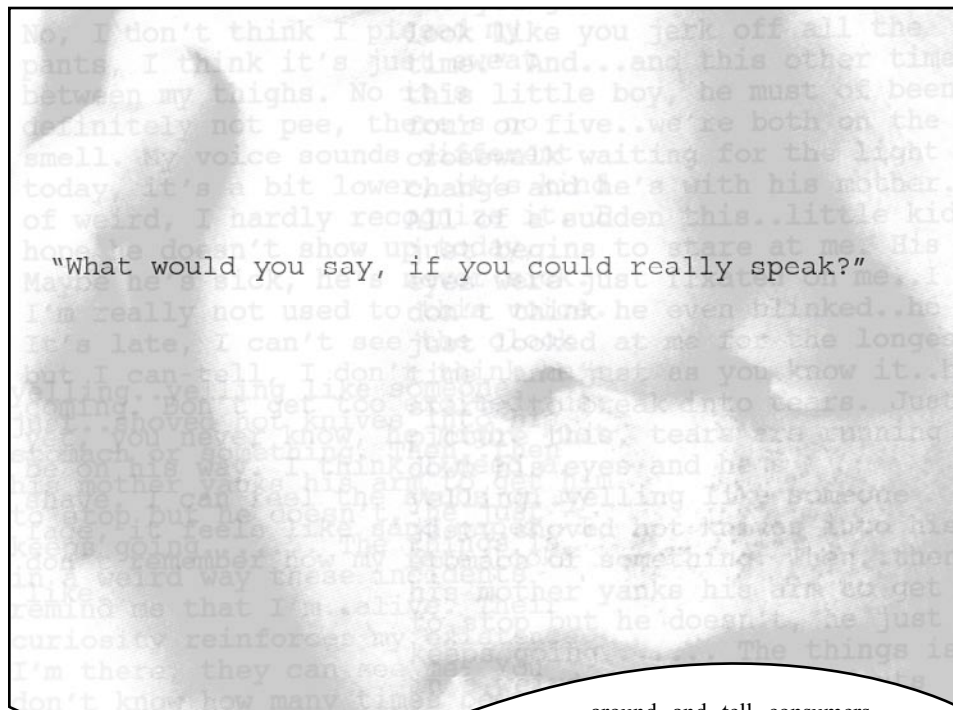
On April 22nd, 2005, Helen Henderson of the Toronto Star wrote an article on this very controversial subject. If you read this article, then you know that Lamia Gibson and I were lucky enough to be a part of this important piece. There were other consumers who participated as well, people who received attendant care services from Tobias House and the Ontario March of Dimes, all giving voice to their frustrations.

Helen Henderson's article brought up many important issues, not the least of which were all types of abuse and the feeling of not being truly considered or heard. From being yelled at in their own homes to being left on toilets for hours at a time, consumers spoke out about the hardships they faced.

Fingers were pointed and very weak explanations were given for the horrendous treatment of consumers. The management of the attendant care projects laid blame on the lack of government funding, saying that they were only able to pay employees \$13.00 an hour and that this was the reason why, sometimes, undesirable people took these jobs, often holding onto them for years. What convoluted logic is that? If attendants aren't paid very well and don't like their jobs, they can always find another one that suits them better. Unfortunately, the good attendants (and yes, there are certainly some good people despite the low wages) do tend to move on, leaving the bad ones behind, hanging on like leeches.

For eight years I received attendant care service from Participation House in Markham. Conditions were bad and I felt that my complaints weren't taken seriously, so I moved to Tobias House in downtown Toronto. At first, perhaps because the site's coordinator had a disability himself, things were ok. He understood where consumers were coming from because he received attendant care services himself. Unfortunately, since his departure six years ago, conditions here have been plummeting downward while the number of complaints has skyrocketed!

Within this past year, consumers have had four separate meetings with the Tobias House man-



agement. One of the consumers who had a communication disability such as myself, told of how a male attendant had yelled at him in his own home, telling him to sit down and shut up! The consumer, frightened and humiliated, went to the coordinator and asked that the male attendant not be allowed to have any more of his bookings. At first, the coordinator agreed, but then rescinded his promise, saying that it wouldn't be fair to the male attendant. Another consumer told of how a female attendant had put her on the toilet, went outside on the woman's balcony and fell asleep for two hours. Even though this female attendant had done the same thing to other consumers, she was neither fired nor disciplined.

During these meetings, Tobias House management takes notes and acts very sympathetic, but rarely does anything substantial to improve conditions. And, at the last meeting, they confessed to us that although they had told us for years that attendants could be eventually fired if enough complaints were compiled against them, now it was declared that because of the union's takeover three years ago, it would simply cost too much in litigation to fire anyone.

Management blames low government funding for the problems with attendant care, and that might have a smattering of truth to it. Partially low funding, partially dealing with unions. Sure. However, from where I'm sitting, and from others who have shared similar experiences, the management of all of these attendant care projects has to share some of the responsibility. Before projects become unionized (and not all are), listen to the complaints of all your consumers and take them seriously. If you learn of any type of abuse, fire the abuser! Don't keep them

around and tell consumers that they have to work things out. Learn how people with disabilities live, find out about the challenges they face, the desires they have. Respect them, emphasize with their plights, and don't utter ridiculous comments like "If you don't like it here, you can always get Direct Funding!" (To get Direct Funding from the government to hire your own attendants, you first have to apply for it, move out of your home and then try to find another one that is accessible and in an area in which you feel safe. It's not a simple process!)

Helen Henderson visited me at St. Lawrence Market to find out if I had suffered any repercussions from her article in the Star. She was seriously worried about my welfare. I told her that the response was pretty much what had expected. The attendants whom I had always had problems with were giving me the cold shoulder, and the attendants I had always gotten along with were behind me 100%. What really upset me, I told Helen, was how the coordinator of Tobias House at my building had responded. Upon hearing that some of the attendants were upset about the article, he went out and bought them all candy. Like spoiled children, they were placated by candy! And what a slap in the face to all of the consumers who have suffered at the hands of these people!

Some people think I'm brave for talking to Helen Henderson, others think I'm crazy. Perhaps the truth lies in between. The thing is, being president of Speaking Differently and being on the mayor's Disability Issues Committee, I see exciting changes about to happen and I wanted to make a contribution of my own. Whatever happens to me, good or bad, I'm glad I spoke out and made the public more aware of what attendant services are really like.

Anne Abbott

ANSWER KEY

Crossword in the previous issue:



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ON THE WEB

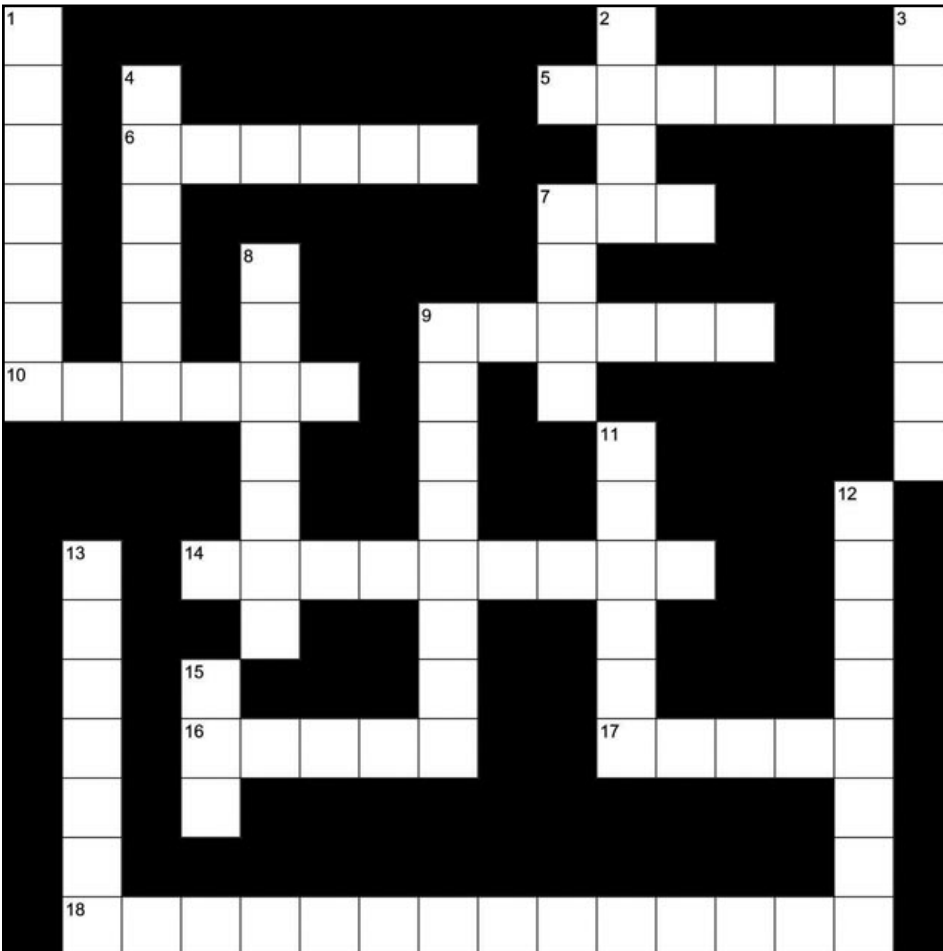
Want to learn more about some of the issues covered in this edition of L & C?
Check out the following SD approved links!

<http://www.aphasia.ca/>

<http://www.aphasia.org/>

http://www.asha.org/public/speech/disorders/Aphasia_info.htm

SD CROSSWORD



Across

5. Dilbert's sidekick
6. Surfacing author Margaret
7. Night flyer
9. Red Sox hometown
10. "Kick it up a notch" chef
14. Two weeks in Britain
16. Gwyneth's daughter
17. Swahili country
18. Pixar's latest release (2 wds)

Down

1. Canoe trek
2. Spanish hello
3. Calgary's July rodeo
4. Gathering of geese
7. Insulin discoverers Banting and
8. Niagara bridge
9. Dime's famous sailboat
11. Hiawatha's nation
12. SNL Producer Lorne
13. Canada's newest territory
15. Afternoon snooze

By Sarah Green