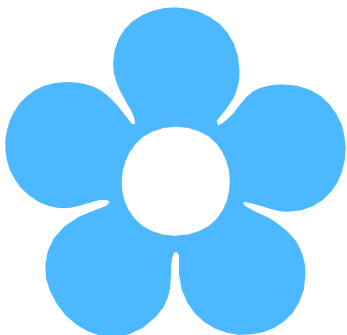


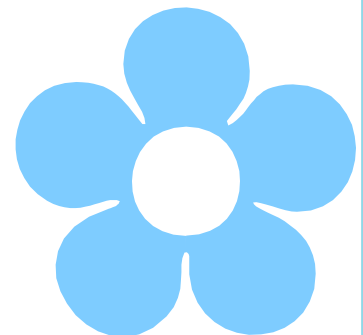
Fluency Island

Souvenir magazine to mark the 4 years
of Fluency Initiative in Mauritius

Articles in English and French



Edited and published by
Friends 4 Fluency
self-help group for persons who stutter
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Welcome to Fluency Island: a message from the editorial team

David Victoire, President of Friends 4 Fluency

Jim Caroopen, Member of Friends 4 Fluency

It is with great pleasure that we address this opening message to all readers of Fluency Island, the souvenir magazine to mark the four years of Fluency Initiative in Mauritius. In the very first place, we would like to thank all the persons around the world and in Mauritius who have contributed articles to this magazine, and who have granted us support in one way or another. We would also like to address a special word of thanks to our parents and loved ones, who have always been present at the moments we needed them most; to our friends and fellow members of the different self-help groups which have existed since 2005; and to all those persons from abroad who have been caring for us and helping us in our journey, despite the miles. We have a very special thought for Mark Irwin, the person through whom the Fluency Initiative has started here, and for Anne Marie Simon, who visited us twice and helped us to grow up and become happy persons, persons who feel free to live, talk and dream despite their stuttering.

Why Fluency Island?

Mauritius is 1,284,264 persons* living together on an island of 1,860 square kilometres, situated right in the middle of the Indian Ocean. Added to this is the diversity of cultures and languages that come from many parts of the world, tightly linked with the history of the island. All this to say that we are first and foremost “islanders” and our view of the world is conditioned by the geography in which we live. Insofar as stuttering is concerned, it has to be said straight away that in addition to all the usual difficulties that persons who stutter (PWS) have to face, here in Mauritius, we have to tackle one additional difficulty: stuttering is perceived negatively by society, and as a result, there is a sort of taboo around it. In simple terms, there are no words to talk about stuttering, and social convention would add that there is no point in talking about it.

A person who stutters is said to be a “gaga” in our local language, the Creole. However, “gaga” is a very pejorative word, which is generally used to make fun of people who stutter, or to tease a fluent person who is having a sudden difficulty to articulate a word or a sentence. In short, being treated as a “gaga” is nearly like being insulted,

but for sure this is always felt as a humiliation. How then would “genuine” persons who stutter relate to others and talk positively about their stuttering, and everything that relates to it?

Indeed, talking about stuttering in Mauritius is always very tricky, and the above gives a measure of how great a breakthrough the launch of the Fluency Initiative in 2005 has been for Mauritian persons who stutter. Indeed, prior to October 2005, there was absolutely no place on the island where PWS could meet and discuss about their stuttering. Four years later, we can note that many things have changed. It is true that there are yet a lot of things that have to be done to improve the social life and wellbeing of PWS, but at least now, there is a place where they can meet, and discuss, and make projects, and learn about stuttering, network with PWS abroad, and finally discover that stuttering is a condition shared by millions of people around the globe.

During the past four years, the Fluency Initiative has brought together many people from all over the island, including PWS, their parents, friends and loved ones, and speech and language pathologists (SLPs). After much concertation

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within Friends 4 Fluency about how to mark this 4th anniversary, we have found it important that we bring together the experiences, thoughts and ideas of all those who have participated to the various activities of the Initiative. Indeed, after four years of focused activity, it is the right moment for us to take a pause and make a review of what has been accomplished to date, and at the same time, to reflect on what needs to be done in future. Thus, the “souvenir magazine project” was born.

However, a big problem arose almost immediately: any magazine should have a title. What would be the title for our souvenir magazine? After much debate, “Fluency Island” emerged as a federating title, as firstly, it takes account of our primary condition of “islanders”, and secondly, it encapsulates our dream to live in an island where PWS have an equal right to be happy, to stutter and to talk about stuttering. In other words, the chosen title points to our dream to make Mauritius *become* a “Fluency Island”, at the exact opposite of the present situation!

The Fluency Initiative

In our local context, the words “Fluency Initiative” refer to all group activities relating to stuttering awareness and self-help that have taken place in Mauritius from 2005 onwards. Herewith is a very brief account of the main events which constitute the Fluency Initiative in Mauritius.

The first self-help group was created on 13th October 2005, following an information meeting that was conducted by Mark Irwin. The group met regularly on Saturday afternoons in Port Louis, and in December of the same year, it was named **Parole d’Espoir**. In January 2006, new members joined the group and many activities were organised, including a “Friends and Family Day” and a “Speech Celebration Day”!

In January 2007, the self-help group joined with a group of parents in Rose-Hill, and created together a registered association, known as **Association Parole d’Espoir**. In the beginning, this collaboration was very successful and a vast media campaign was set up to launch the association and

promote the self-help group. Following this, some 30 new PWS joined the group and regular meetings were organised over 16 weeks. In June of the same year, Anne Marie Simon, SLP and Secretary General of Association Parole Bégaïement (France) visited us for two days; she conducted a half-day group therapy, and participated to awareness efforts by taking part in media programs.

However, after some months of fruitful collaboration between the group of parents and the self-help group, things started to turn sour and a painful conflict cropped up between the two parties. The group of parents seemed to be at an advantage since they kept control over Association Parole d’Espoir, but thanks to their remarkable sense of friendship and solidarity, the self-help group survived and its cohesiveness was strengthened. A new name was chosen, **Fiends 4 Fluency**.

Furthermore, after a few months, Association Parole d’Espoir was winded up due to internal conflicts between the parents. Thereafter, some of the parents, together with a couple of PWS who had left the self-help group, created a new registered association, known as **Association Soutien et Rééducation aux Personnes Bègues** (*Association for support and re-education of PWS*). Eventually, the two parties came to reconciliation and now both the association and Friends 4 Fluency work together in good intelligence to further awareness about stuttering and the welfare of PWS in Mauritius.

In March 2008, Friends 4 Fluency organised an **Intensive Therapy Week** with the precious help of Anne Marie Simon, and Aude Fresnay, a SLP from Reunion Island. This therapy week turned out to be a defining moment for us all. After the intensive therapy week, we could sincerely start to accept ourselves as persons who stutter, and lead our life in a different way; in a way that does not prevent us from reaching out for our dreams, in a way that makes us feel in harmony with ourselves, with our stutter and with all other people around us. Additionally, the therapy week reinforced our friendship and team spirit, and gave us the

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motivation and impetus to change Mauritius into a “Fluency Island”.

During 2009, Friends 4 Fluency held regular meetings, and we invited PWS from all over the island to join us. On 12th September last, a special meeting was held at Ebène to celebrate the 4 years of Fluency Initiative in Mauritius, and all previous participants, including the parents of Rose Hill, were invited. Another milestone of the Fluency Initiative laid in 2009, was the election of an “Équipe de Direction” (Board) to *take in charge the future of Friends 4 Fluency*. Indeed, Jim Carooopen had expressed his intention to retire from the “leadership” of the group, and after much reflection, it was decided that an “Équipe de Direction” of three members would be elected. After a democratic and transparent vote, David Victoire has been chosen to be the President of Friends 4 Fluency, and he will be seconded by two vice-presidents, Yasvin Somoo and Briguel Babet. The special meeting of 12th September last also served as an investiture ceremony for the new team. Jim stays on as a member of Friends 4 Fluency, and he will assist the new team, as and when they request his advice.

In a nutshell

It is the first time that Friends 4 Fluency is editing and publishing a magazine, and on this account, we would like to request the kind understanding of our readers. The approach that we have chosen for the magazine was to invite the members of Friends 4 Fluency, all previous participants and our friends from abroad to contribute articles on any subject of interest to them. We have been very

nicely surprised by the number and quality of articles that we received, and we would like to say

a **VERY BIG THANK YOU** to all our friends, both local and from abroad, who have written articles for our magazine.

All articles received have been published *in extenso* and in the language in which they have been written, with the exception of one article written in English by Deborah Plummer (page 18), which has been translated by Caroline Martin, and therefore appears in French as well (page 46). We would like to thank both of them for their much appreciated contribution. Last but not least, we would like to thank our friend Brinda Runghsawmee who has reviewed and proof-read all the articles in this magazine.

For the sake of simplicity, Fluency Island has been divided into two sections: an English section, which starts on page 4, and a French section, which starts on page 36; each section has its own table of contents.

So, here we are! Have a nice time reading our magazine. We hope that the magazine will be of interest to both local and international readers: PWS, SLPs, parents and every person curious to know more about stuttering and PWS. Do not hesitate to talk about Fluency Island, and share it with your friends, family, and people around you.

We would be very happy to receive your comments, questions and/or suggestions on our magazine, and we look forward to hear from you!

Friends 4 Fluency

self-help group for persons who stutter

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*Source: <https://www.cia.gov/library/publications/the-world-factbook/geos/mp.html>.

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Perceptions on stuttering in Mauritius: an interview with Liinaa Muttur, speech and language pathologist

Jim Caropen

Member of Friends 4 Fluency

As my contribution to Fluency Island, I wanted to explore into the perceptions of the general public on stuttering. As a person who stutters, and a member of a self-help group, I had always felt that there is something weird about stuttering in Mauritius. It is always difficult to discuss openly about stuttering, and people who stutter always feel bad about being persons who stutter (as if this was a shame or a curse). The first time that I was able to put a word on this indelible feeling was during the Intensive Therapy Week of March 2008; Anne Marie Simon evoked the word “taboo” to describe the way stuttering is construed in Mauritius. From this moment, things became simpler, as there was a word to describe this unspeakable and uneasy situation, for both fluent persons and PWS.

I was very happy to make contact with Liinaa Muttur, a speech and language pathologist (SLP) and audiologist, who is also a consultant SLP within “Association Soutien et Rééducation aux Personnes Bègues” (ASRPB) based in Rose Hill. I am very thankful for her invaluable contribution to my project, and to Mrs. Roseline Bugwondeen, the president of ASRPB, who has facilitated the contact. The views of Liinaa are very enlightening on the perceptions of the general public on stuttering, and how this affects PWS. Two points that I would like to highlight are the importance for PWS to follow speech therapies with SLPs, and for self-help groups to work in close collaboration with SLPs. This is not presently the case in Mauritius, and my message to PWS today is that this state of things should be changed. SLPs are our most precious allies in our quest for fluency, and we must go to them!

1. Are there any researches on the number of persons who stutter in Mauritius?

To my knowledge, there are no truly reliable researches that have been done on the incidence of stuttering in Mauritius. I would say that figures which may have been brought forward with regard to stuttering in Mauritius can only be viewed as estimates of the actual situation. The tendency is more to rely on figures found in researches conducted abroad to estimate that approximately 1% of the population has a problem of stuttering.

2. According to you, is there a taboo around stuttering in Mauritius? And if yes, how would you explain this?

In my opinion, stuttering is surrounded by a very deep-seated taboo in Mauritius. Indeed, there is barely any awareness of the general public about stuttering, and as a result, people do not know what it actually is. The subject of stuttering is rarely treated among the Mauritian people. Regretfully, till now, even the media has rarely addressed the stuttering issue as a subject of suffering. Rather, we often see a stammering person in entertainment shows, advertisements

and movies meant to make the audience laugh. For most of us, we prefer to treat stuttering as a matter of ridicule, something to laugh about, a sort of light entertainment. This in turn worsens the problem, as PWS feel offended and hide away with their suffering.

3. *What have you gathered about the perceptions of the general public on stuttering and persons who stutter in Mauritius?*

I think it would not be right to generalize the perceptions of one and all. There are people who are truly concerned and who genuinely understand PWS. Unfortunately, such people constitute a minority. I think it would be wise to view stuttering as a disorder, not an illness. PWS are treated as stupid persons, and at times they are even assimilated with the mentally disturbed. Indeed, and it is sad to say, people feel concerned about stuttering only when a member of their family, or a close friend, is affected by it.

4. *According to what you have gathered from your patients, would you say that persons who stutter suffer from stigmatisation in Mauritius? And if yes, under what forms do this happen?*

To be honest, I would say that if you are a person who stutters, Mauritius is not the ideal place for you to stay! Yes, PWS are definitely stigmatised here, but this happens in an indirect, or I would say, invisible manner. In other words, the way people around them would behave, and the choices that would be offered to them, would increase the chances that they develop into an introvert person. However, no one will know that this is due to stuttering. Everyone will finally opine that the person is just introverted, reserved and “not very talkative” by nature. The root cause (that is, stuttering) will never be identified or rather, will never be admitted. Sometimes, it is the

person’s whole life that goes wasted. He ends up doing a job he would not have chosen if he did not have stuttering and often ends up ordering some item he hates at the restaurant just because it is easy to say that word to the waiter. I would like to add that stigmatisation of PWS also operates within the family. Sometimes, family members are embarrassed to go out with a brother, a sister or other person who stutters, and also, PWS are frequently kept apart when relatives and friends come to visit the family.

5. *Would you say that persons who stutter suffer from discrimination in the workplace? And if yes, what forms do this take?*

This is widely variable and depends mostly on the profession. As you know, communication is essential in any situation, and the more so in the workplace. To begin with, the person who stutters will suffer from a negative bias at the very moment of the interview. It is also frequent that PWS miss opportunities of promotion in their work due to their stuttering. Interaction among colleagues can be difficult as there is no awareness about stuttering on the workplace either.

6. *What do you think of self-help groups for persons who stutter?*

One thing I have noted from my professional experience is that only a small percentage of PWS would come to speech and language pathologists (SLP) to follow speech therapy. Indeed, before going to see an SLP you have to admit that you have a problem with stuttering. And you have to admit it to somebody who does not share your problem since s/he does not stutter. This can be very difficult for many PWS. With regard to self-help groups (SHG), I believe this is a very positive development for PWS. However, it is essential that self-help

groups go together with therapy with SLPs. I strongly advocate that SHG and SLPs should work hand in hand.

7. Do you have a message that you would like to convey to persons who stutter in Mauritius?

I would just like to share the following with them.

- Don't feel guilty about stuttering; it has a medical origin. It is not your mistake.
- Don't keep it for yourself: talk about it. There are people who can help you!
- Taking the first step is the most difficult. Go out and look for help: either join a self-help group, or visit a speech and language pathologist whom you are comfortable with, and preferably, go for both.
- There is presently no cure for stuttering, but there are several ways which can help you speak more fluently.
- Do not let stuttering control your life; rather you have to control your speech. It is possible! Many people have done it before you.

An interview with Keith Boss

Yasvin Somoo

Vice-President of Friends 4 Fluency

*In 2006, I was searching for help on the internet with regard to my stuttering, and I met Keith Boss. He helped me to identify a self-group in Mauritius; it was **Parole d'Espoir**. Since then, I have made a lot of progress on how to better handle my stuttering. As a way to thank Keith for his helping hand, I have decided to make an interview with him. This will give the opportunity to PWS in Mauritius and around the world to know better my dear friend Keith, a generous and very active young person...*

1. Keith, who are you?

Hello, I am Keith Boss. I am 71 years young, and I live in the UK. I am a Board Member of the British Stammering Association. I began stammering as a child. I decided to 'do something about my stammer' in 2006. Now I love communication and giving speeches.

2. What does stuttering means to you?

With hindsight it helped me to lead a restricted life. It was a happy life. I had a happy family. I did well working on computers. But when I changed in 2006, I

realised just how much I limited what I tried to achieve before 2006. Now stuttering means nothing to me at all. I rarely think about it when I speak.

3. Tell us how have you deal with your stuttering?

I have learned that what we focus our minds on tends to happen. If I focused my mind on not stuttering, my mind has to remember stuttering so I am focussing on it. What I do now is to focus on communication and to learn to be a better communicator day by day.

4. Tell us more about your role in the ISA.

I was on the Board of the International Stuttering Association (ISA) and I was Chair of Outreach. This enabled me to link with people who stutter around the world. In March this year I resigned from the Board as my time was not being well spent. Recently, there is a possibility of change in the ISA and I may be working with them again. We will have to wait and see.

5. How can the ISA help Mauritius to develop the Fluency Initiative further?

The ISA can encourage you to start more self-help groups, where you can practice your techniques in a friendly environment. I would urge you to start up a Toastmasters club, again where you speak in a friendly supportive environment. If you or the ISA raised money to cover air fares and living expenses, we might send one of the Board and a Speech Language Therapist to visit you, to talk to anyone you like.

6. What do you mean by Toastmasters club and how could it help us?

The Toastmasters club I belong to is <http://www.angliatoastmasters.co.uk>. It is part of the International club started in the USA (<http://www.toastmasters.org>). Toastmasters meetings help members to improve their communication and to improve their leadership skills. The environment is a friendly place where members help each other. We learn so much about body language; owning the speaking area; pauses etc. When you

have some speaking tools which help you, you can use them here to improve your confidence and skills.

7. How many local associations do you help and how do you manage your time for these?

I work on the BSA Board. We have four meetings a year. Some BSA self-help groups have several open days a year I try to attend and a conference every other year. I usually do a workshop for them. Time is always a problem as I do many things in my current life.

8. Tell us more about the website of The Indian Stammering Association (TISA) that you have created.

There are two actually: one in India and one in Pakistan. Both have active websites and Yahoo groups, and both have a local leader who wants to increase the awareness of stammering in their own country. They encourage more self-help groups to start and help each other to grow in numbers. Every opportunity is used to talk to the media and get some publicity.

9. Do you have a message for the stuttering people in Mauritius?

Go <http://www.mnsu.edu/comdis/isad12/isadcon12.html> and visit <http://www.mnsu.edu/comdis/isad12/isadcon12.html>. It is the ISAD online conference. You will read about other people around the world who stutter. You will realise, you are not alone. Add your comments to all the articles you read.

In addition to the above interview, Keith Boss has also contributed an article of his own. Kindly refer to page 31.

Thoughts about stammering in Mauritius

Liinaa Muttur

Speech and language pathologist and audiologist

When I was asked to write an article about stammering in Mauritius, I said yes instantly. Quite simple, I thought at first! But it turned out to be more difficult than I had thought since we rarely talk about it in Mauritius. If I am not a Person with Stammering (PWS) or I do not have any dear one who suffers from the condition, then there is a high probability that I would very rarely come across the word 'stammering'. Or if I do happen to come across it, my mind will not dwell on it for long. So, why has stammering remained such a taboo here in a country which is ready to accept more than one other controversial matters?

Stammering has quite a high incidence in Mauritius. It is a problem which we have to talk about more often and more openly. Many of our fellow countrymen suffer from this difficult speech condition. Unfortunately, most suffer in silence or do not get the support they rightfully deserve from others. Somehow, injustice is done to them and each one of us can be instrumental in improving the situation.

My message to the person with stammering ...

I totally agree that it is very hard (even nearly impossible!) for somebody who has never had a painful stutter to understand just how damaging the affect can be on one's life, confidence and self-esteem. In my opinion, even a speech therapist cannot fully identify with you as a person with stammering. However a person who really cares can imagine your plight fairly well. Believe me, there are people who do not stammer but who care genuinely.

My message to you as a speech therapist would be to focus on yourself. Realize the importance of having your own mind. Do not let the opinion of others control your self-image. Those who laugh or mock you are not worthy of your consideration. If they cannot accept you with your speech difficulty, too bad for them!! You are the best person to know your actual worth and the way you talk does not define who you are. I can be speaking perfectly and still be a shallow person.

Share your thoughts with others. A sorrow shared is a sorrow lessened! The lighter you are in your mind, the less painful will be your speech

experience. Do not avoid situations as far as possible. We live life only once. Do not miss out on nice experiences just because your speech will provoke cheap laughs from short-minded people. Be yourself! Join self-help groups and see a professional to at least try out therapy techniques which may or may not work with you.

My message to the others (persons who do not stammer) ...

Do not be quick in judging the person with stammering. Stammering can affect anyone. Tomorrow, it can be you or someone who means a lot to you. Think twice before you laugh or ridicule a person who is stammering for example when you are watching slapstick comic shows portraying stammering as fun material.

But on the other hand, do not show pity. Advice like "breathe properly", "don't worry", "don't be afraid" though well-meant is not always helpful. Try to focus on **what** is being said rather than **how** it is being said. Give the person time to speak, do not hurry him. Telephone conversations can be a big challenge for many PWS. If the person is on telephone, do not rush him or disconnect the phone if he is silent for a while or is taking longer than usual. If you see a person stammering, do not assume he is stupid or confused. He just has a speech difficulty.

As a concluding thought, I believe it is high time to change the wrong perception most of us have of stammering. I think it should be a collective work. Together let's make sure that we do everything we can to prevent the life of another PWS from being made more difficult because of us!

Stuttering and Stuttered Speech Syndrome: the difference and what it means

Mark Irwin

Former President of the International Stuttering Association (2001-2007)

I am delighted to accept Jim Caroopen's invitation to write this essay. I first met Jim in 2005 in the Pizza Hut at Port Louis, and have since been extremely impressed by his ability to not only help himself but to also provide leadership in the help of others. In addition I believe Jim's story illustrates a point that continues to be overlooked throughout the world, namely that the physical event of stuttering needs to be separated from its psychosocial pathology, so as to bring forward a better awareness of what stuttering is and what can be done about it. This distinction is best made by using separate terms, Stuttering for the speech events, and Stuttered Speech Syndrome for situations where stuttering and associated clinically significant psychopathology combine.

Labels and Descriptive Terms

Did you know that between 50 –75% of people who stutter can be diagnosed with the additional disability of social anxiety disorder (SAD). The key point is that this figure is **not** 100%. Therefore it can be said there are two subgroups of people who stutter, those with SAD and those without it. This has clear implications for the provision of stuttering therapy, for public awareness messages about stuttering, and for recognition of stuttering as a disability. To stress the point again it needs to be appreciated that people who stutter not only have to deal with dysfluent speech, which is an obvious disability, but **may** also have to deal with clinically significant psychological distress, best labelled as the disability of social anxiety disorder. Hence there is a difference between **Stuttering** and **Stuttered Speech Syndrome**.

Mauritius Meeting

But back to Jim and our first meeting. An obviously shy Jim, speaking in an extremely quiet voice, told me how he had struggled with stuttering for most of his life and how it was now affecting his ability to socialize with co-workers at meal breaks and perform in interviews. In general it was dominating his thoughts and limiting his social and professional life. Jim had sought speech therapy on 3 occasions and had achieved only limited

success. Jim's story mirrored my own at a similar age and I felt I understood his concerns very well.

I told Jim about how I had recognized my fluency was not about any obvious physical limitation in speech (I could speak well on certain occasions) but more a psychological limitation. This psychological limitation had two aspects relating to **perceptions** and **habits**. On certain occasions it seemed my fluency (or lack of it!) was related to my perception of the interaction with my communication partners. That is when talking to the very young or elderly I perceived myself to be in a relatively stress free position and I spoke with more control. However, when under perceived time or performance pressure from "authority" figures my fluency was erratic and I blocked often.

That realization was key for me. I understood that for my speech to change I needed to alter both my perceptions **and** my habits. I told Jim of my return to university to study psychology and of my avid reading of all matters relating to changing attitudes and behaviour. It was from this I learned that a fundamental requirement was the need for me to practice success in a "winning" environment (a situation in which I expected to succeed), to then build on that success by entering a slightly more difficult situation, and once mastered

continue this process. Also “success” was to be defined as not only speaking fluently, but saying exactly what I wanted to say as well as feeling relaxed and indeed “enjoying” the communication process.

We talked for a long while as I referred to the issues that were important and necessary for me. They were:

1. **Become more assertive.** I had to realise I had as much right to be there and could take as much time as suited me. It was silly but even though I was the dentist I had been giving away my power to the patient. Clearly I had been doing a similar thing in my interactions with other people outside my work. My strategy was to choose to watch (either directly or through television and film) and to spend time with assertive people, knowing their attitudes would rub off. Observational learning was extremely important for me.
2. **Increase self esteem and self confidence. Know more, read more, take more courses.** My issue was communication - I read all I could about body language, improved my English expression by studying grammar and developing my vocabulary, and furthered my general knowledge by studying psychology, anthropology and history. I figured that if I was going to speak well I also needed to have something to speak about. Also having more knowledge would improve my confidence.
3. **Focus on what I could do right** in the communication process (not on what I was doing wrong - i.e. being dysfluent). I learnt to smile more, to relax, to listen and breathe at the same time!
4. **Monitor my anxiety level in relation to that of the other person.** I developed this technique which I called Controlled Emotional Response. I would simply focus on connecting with the emotional response of the person to whom I was communicating (rather than worrying about how I was performing!) by giving THEM a score from zero to 10 as to how anxious I perceived them to be. I would then focus on relaxing sufficiently so as to

achieve a score the equal if not less for myself. In doing this I was able to stand guard and stop the old uncontrolled feelings of anxiety from overwhelming me like they had always done. I was also taking the stress off myself by focusing on someone else. In addition, paying attention to what the other person was feeling also helped me in the communication process.

5. **Restructure negative associations. Positive Replay.** If for some reason I had had a negative experience rather than beat myself up about it (like I had always done in the past) I would replay the situation in my mind. But this time the replay was changed to have me perform positively. That is to perform in the way I would have preferred and certainly in the way I would like to when again in a similar situation. In this way I trained myself to give an automatic positive response when presented again with the same situation.
6. **Lower resting level of anxiety. Use of Meditation and Self-Hypnosis.** Have you ever noticed how some people seem to be more relaxed than others? I have and I resolved to become more relaxed myself. I felt that I had been anxious for so long that a hyper anxiety state had become part of me. I was so used to being anxious that being anxious was normal for me. Anyway I studied meditation and self-hypnosis and developed a mantra for myself.

MEDITATION. How I did it. Start in a chair in a quiet room and practice relaxing ideally 3 times per day. Return to that chair each time and soon the chair becomes associated with relaxation. So it becomes easier to enter a deeper state of relaxation and to enter that state more and more quickly each time you sit in the same chair. Then while in that chair focus on the tip of a candle flame until you "see" a line of energy between your eyes and the candle flame. Breathe in the energy from that flame calling it in turn poise, strength and self confidence. Breathe out stress anxiety and confusion. A variation is to "see" stress, anxiety and confusion bundled in a canoe

about to float over a waterfall and out to sea - way out of your life!

SELF-HYPNOSIS. How I did it. Again in that same favourite chair, while calling to mind several people who I regarded as outstanding communicators, I read myself the following passage.

"As you become.....and as you remain...more confident and relaxed each day....so you will become more confident and relaxed in the presence of other people... no matter whether they be few or many.. no matter whether they be friends or strangers. In everyday life... you will enjoy opportunities to speak....and do so with intonation and rhythm and breath support...so as you speak you will become completely relaxed both mentally and physically..quite calm and composed. If ...at any moment...you should begin to feel difficulty with a particular word...You will stop speaking immediately for a moment or two... And during that brief period of silence, the muscles of your face..your throat.. your tongue and your lips..and the muscles of your chest will relax completely..so that when you speak again the difficult word slips out quite easily. You will cultivate the habit of speaking with POISE where P stands for Projection of voice, O reminds you to Open the mouth and articulate every sound, I reminds you to inhale, S stands for Smile and E reminds you to speak with Effortlessly."

In addition to this approach, which I believe was of significant benefit, I would also programme my mind before going to bed by reminding myself of all the things I had done well that day and look forward to doing even better the next day.

7. **Practice Success. Practice in a winning environment.** I think it is possible to build on success until you reach the limit of your physical and mental abilities. A strategy for achieving this was outlined in a book by Leonard Morehouse "Theory of Maximum Performance". The central idea was the value of practicing in a winning environment. He quoted a study in which 2 groups, one successful sportsmen and the other a general group where

introduced to golf. The various strategies of how individuals in each group went about developing their skills were analysed. It turned out that individuals in the general group were quick to pick up the most difficult club, one wood (or driver), and try to blast the ball as far as possible. The sportsmen group in contrast chose to start with something they expected success from. Their approach was to pick up one of the easiest clubs, a 9 iron, and chip relatively easy shots before building up their skills with gradual exposure to clubs of increasing difficulty. The last thing they attempted to do was to use the difficult driver! The general group had limited success and often gave up in frustration while the sportsmen group used the success to build self confidence and enjoyed proceeding to the next level of challenge. I applied this strategy to learning to talk on the telephone. I was so terrified of the telephone I had to make my "success steps" very small in order to be situations where I had an expectation of doing well.

My steps in order were:

- Learning to relax in my favourite chair (in a quiet corner of my bedroom)
- Learning to relax in my favourite chair while looking at my telephone
- Learning to relax in my favourite chair while hearing the telephone ring
- Learning to relax in my favourite chair while holding the telephone to my ear
- Learning to relax while watching myself in a mirror hold the telephone
- Learning to relax while speaking with the telephone and watching myself in the mirror.
- Learning to relax while ringing and speaking to a friend on the telephone
- Learning to relax while making calls to strangers. (hotel and airline staff)
- Learning to relax while talking on telephones other than the one in my bedroom! (It seems funny but for a while I could only be

fluent on that one bedroom telephone.)

- Learning to relax while using the telephone in front of other people.

After success with each step I would move on to the next with a feeling of anticipation and excitement. But I realised from my studies in psychology I needed to reinforce the success. Simply doing it once was not enough. I found it necessary to practice each step 2 to 3 times per day and make at least 10 calls per day. I also realised from my psychology studies that I had to be constant in my practice. The longer I left it between practice sessions the more likely I was to return to the old fears.

I have also used this strategy to develop my speaking ability and am pleased to report I have now reached Division standard in Toastmaster Public Speaking competitions.

My steps here involved:

- Learning to speak well when alone (rehearsing my speech)
- Learning to speak well at my stuttering support group meetings
- Learning to speak well at general meetings using Delayed
- Learning to speak well at Toastmasters

My next step is to speak well publicly at any time.

8. **Keep on track. Join a Support Group** It is well accepted that support groups have a therapeutic value of their own. I have found many benefits. They link us to people with a common interest which helps keep us on track with our plans for change. Also this link provides an opportunity to develop socially. (This is important for people who stutter who need to make up for lost time spent avoiding social situations.) But more than this it is important to have discussions because they help us consolidate our

ideas, develop our self identity and check emotional reality. (PWS who have not engaged in discussions have missed an important opportunity for development.) The value of this to our psyche cannot be underestimated. An obvious if extreme example is the well known impact of solitary confinement which was used as a form of torture and often lead to insanity in the victim. Another value of a support group is that it provides an opportunity to help others. I believe this to be a prime human need and certainly have found it provides soul food. With it a centeredness comes which in turn leads to a greater feeling of general relaxation and improved speaking and communicating.

9. **Change Self Image as a Speaker. Record Success. Keep a Journal.** Write down when you spoke well. (describe who, when and where.) I found reviewing the ever expanding list of successful speaking situations to be extremely powerful in changing my speaking self image. I think too often people who stutter have over-emphasized their limitations as communicators. To my mind it is important that this false image be corrected by receiving validation as a speaker wherever possible. The journal helped me do this.
10. **Keep a sense of humour and a realistic perspective. Whatever we may sometimes feel, stuttering is not the worst thing that anyone has ever done in the history of mankind.** I find I communicate best when I allow myself a few dysfluencies and let go of the need to produce perfect speech. When and if, the dysfluencies come I take it as feedback to slow down and breathe more. I no longer feel as embarrassed, ashamed or as tense as I once did. With this approach I feel certain I am not only decreasing stuttered speech but I am also decreasing if not eliminating stuttered feelings which after all are the real cause of the pain of stuttering.

My perspective is a result of inspiration from the following statements:

- Life is a journey not a destination.
- The journey of a 1000 miles starts with a single step.
- (On that journey) Obstacles are only opportunities in disguise.
- The smallest action is better than the noblest intent.

The above points relate to specific action that can be taken to improve speech and communication. But I also think it is important to have a clear life philosophy in order to build a foundation from which this action can be taken. I have drawn a feeling of inner peace (which I believe provides me with general relaxation and better speech and communication) from the philosophy outlined in the verses found in what is known as the *Desiderata*. It reads:...

"Go placidly amid the noise and haste, and remember what peace there may be in silence. As far as possible, without surrender be on good terms with all persons. Speak your truth quietly and clearly; and listen to others, even the dull and the ignorant: they too have their story. Avoid loud and aggressive persons, they are the vexations of the spirit. If you compare yourself to others you will become vain and bitter, for always there will be greater and lesser persons than yourself. Enjoy your achievements as well as your plans. Keep interested in your own career, however humble, it is a real possession in the changing fortunes of time. Exercise caution in your business affairs, for the world is full of trickery. But let this not blind you to what virtue there is, many persons strive for high ideals, and everywhere life is full of heroism. Be yourself. Especially do not feign affection. Neither be cynical about love, for in the face of all aridity and disenchantment it is as perennial as the grass. Take kindly the counsel of the years, gracefully surrendering the things of youth. Nurture strength of spirit to shield you in times of sudden misfortune. But do not distress

yourself with imaginings. Many fears are borne of fatigue and loneliness. Beyond a wholesome discipline be gentle with yourself. You are a child of the universe, no less than the trees or the stars, you have the right to be here. And whether it is clear to you or not no doubt the universe is unfolding as it should. Therefore be at peace with God, whatever you conceive Him to be, and whatever your labours and aspirations, in the noisy confusion of life keep peace with your soul. With all its sham, drudgery and broken dreams it is still a beautiful world. Be careful. Strive to be happy."

Conclusion

Jim appeared to listen well and I encouraged him to hold a public meeting with the aim of forming a self-help group. Jim, despite his anxiety, faced his fear, made the necessary arrangements and contributed invaluable to the meeting held in Mauritius later that month. More than that he faced another fear and recorded himself on videotape for the first time. In facing his fears and succeeding, Jim had taken steps on recovery from both his stuttering and the anxiety about it.

I believe the steps I have outlined above are similar to the ones taken by Jim and others whose lives are no longer significantly limited by their stuttering. While I (and they) may still stutter we no longer let stuttering consume our thoughts and significantly limit our actions. We no longer have ***Stuttered Speech Syndrome***.

Footnote

I have received ideas, inspiration and encouragement from many sources and I say thank you to my friends and fellow travellers who have helped my efforts. Too often as people who stutter, we can be unnecessarily hard on ourselves and each other. I have valued the support I have received and the opportunities that have been presented in working with others. I hope this essay serves as a guide for others taking the same journey. For those interested in reading more on the difference between Stuttering and Stuttered Speech Syndrome please refer to www.stutteredspeechsyndrome.com.

What is the real role of self-help groups for people who stutter?

Masuhiko Kawasaki

Japan Stuttering Project, ISA Board of Director

Congratulations on the 4 years of the new group for people who stutter in Mauritius! I am a Board member of the International Stuttering Association and a member of the Japan Stuttering Project. To congratulate you on the launch of your new project I would like to share with you my thought about the role of self-help groups for people who stutter.

First, about myself, I started stuttering before I entered elementary school. My parents always told me, "Don't stutter." And they denounced stuttering. So, I felt that stuttering was a bad thing and that I, as someone who stuttered, was an inferior child. The symptoms of my stuttering were not so severe; I was always changing a difficult word that I wanted to say to a different word that I could say easily. In this way, I was kind of deceiving myself. I denied my stuttering and kept hiding it. Also, I was always trying to avoid situations that involved self-introduction or speaking on the telephone.

About 25 years ago, when I was working at my father's company, the financial situation of the company became very bad. At that time, I believed that my stuttering was the cause of the company's poor financial situation. But then, one day, I realized that even if my stuttering were to disappear, the company's situation would still not change. At that moment, I realized that I had not been putting in my best effort to date, and that the reason for the company's poor situation was not my stuttering, but my lack of effort in performing my job. After that, I felt relieved. I began to work hard and the company's situation improved steadily. I became more and more confident about my job; however I still had a huge complex about talking.

About 17 years ago, I started studying social welfare and participating in volunteer work in my spare time. I also tried many forms of therapy, including psychotherapy. In one of the therapy sessions, I could express my feelings about my stuttering and I felt better. Until then, I could not

express my emotional feelings. However, the result of the therapy only enhanced my negative feelings of stuttering. One day when I attended a different psychological workshop, I met Mr. Shinji Ito, who is the Executive Director of the Japan Stuttering Project and who also organized the First International Conference on Stuttering in Kyoto, Japan in 1986: I talked to him about my stuttering and he listened to me in real earnest. He told me that it was O.K. to avoid the situations in which I had to speak. He also told me not to feel guilty about avoiding these difficult situations. It was a big relief for me to hear those words. Then I attended a JSP seminar and I met many people who stutter. When I saw them, I had 2 different feelings at the same time. One feeling was that I did not want to be seen as one of them. The other feeling was that I envied them and I wanted to become like them because they seemed very happy and positive even if they stuttered a lot. They seemed to be at peace with themselves, while in my case, I was always struggling, trying to hide my stuttering. After that JSP seminar, I started to attend weekly JSP seminars that are held every Friday night, and within a few weeks, I became much more accepting of my stuttering. In addition, I began to realize that stuttering was a kind of gift. It allowed me to be more open-minded, and it provided motivation for me to study and learn more about things like psychotherapy, and human behaviour. All in all, I think that stuttering has enhanced my development as a human being, and I feel that this has positively affected my business and my family life. And as a bonus, it has allowed me to become a part of a wonderful group of people, many of whom I consider to be very good friends.

At this time, I would like to touch upon the real role of self-help groups for people who stutter. First of all, a group whose only focus is the “treatment” of stuttering is, in our opinion, not really a self-help group. Rather, such a group is more like a clinic that tries to provide a medical cure. We believe that the role of a self-help group is to allow its members to support each other through speaking and listening. That’s why self-help groups shouldn’t denounce the disorder itself. And we, at JSP, do not denounce stuttering itself. We do not focus on fluency shaping, a reduction of symptoms nor the cure of stuttering. Some people may wonder why the cure or reduction of stuttering is wrong. We believe that if you focus only on the cure of the disorder, you may promote the idea that the disorder is a bad thing and you may feel that you should get rid of it. This creates a negative self-image. So we focus primarily on self-acceptance, striving to grow within ourselves, and learning to live well with stuttering.

Many people have many different disorders, problems, traumas, painful experiences and so on. If such disorders are easy to heal, those people will be O.K. However if they are difficult to cure with modern medical science, if those of them cannot be healed for many years, if you cannot do anything to deal with it, you may suffer alone. Then what can such a person do? If the person is worried alone, his worrying may go round in circles and he may sink in misery. At that time, if he meets other people who have similar experiences and he talks about his experience or his worries in his own words, and he is listened to attentively by them, he can explore another way of living.

Then what really happens in the self-help groups? We have lots of painful experiences. For example, we cannot say even our name, or we cannot be understood when we talk to other people. In the self-help group, by seeing one person talking about his painful experience and other people listening to him in real earnest, you can feel you are O.K. to talk about yourself here. Then, after you have talked about your experience, the following things may happen.

1. You may feel that a heavy weight has been lifted off your shoulder.
2. You may be able to see yourself much more clearly.
3. You may realize it’s O.K. to be worried.
4. You may feel like you are in the company of old friends, though you have only recently met these people.
5. By sharing information, you can see your stuttering objectively.
6. You can develop a new sense of values and you can create a positive lifestyle.

Here, let’s think of 2 groups. One group thinks of their disorder negatively. The other group thinks of their disorder affirmatively. In the first group, they may feel comfortably by talking and saying “We can understand your pain and sadness.” However there is a risk that that group may enhance the negative feeling of the disorder. That is why this is their limit, even though they may feel comfortable. On the contrary, in the other group, by accepting their pain and weakness, they realize that they are O.K. even if they have feelings of depression and worry. By talking and sharing their feelings, they begin to create a positive self-image. By accepting themselves, they can get the energy to face real-life situations in society.

When a person starts to realize that it is O.K. for him to stutter, we, our self-help group, encourage him not to be afraid of interacting in society. We think, “To attain fluency and to build up confidence, the best way is to have a lot of opportunities to speak in everyday life.” When a person who stutters encounters problems and gets depressed, the members of the self-help group will listen to the person and think about the problems together.

Facing stuttering doesn’t really mean dealing with the symptoms of stuttering. It means facing how the person is affected by stuttering. Many people allow the symptoms of stuttering to control or

heavily influence their daily behaviour. As a result, their attitude and their character become negative. Facing stuttering means realizing that the problem is not really stuttering itself, but how we react to it. Once we realize this, a big change begins from an interest in our stuttering to an interest in our life.

We, at JSP, are opposed to the idea that stuttering should be cured. So, then, some of the readers may be thinking that JSP makes no efforts toward overcoming stuttering. Well, we would disagree. We concentrate our efforts on learning to live well with stuttering, not to eliminate our stuttering or reduce symptoms of stuttering.

Therefore our weekly seminar has the following 3 principles.

- 1. To study basic information about stuttering.**
We learn the cause of stuttering and the effect and the limit of therapies and treatments.
- 2. To increase our ability to communicate with others.**
It is possible to communicate with other people cheerfully, even if you stutter. To increase the ability, we provide comprehensive training about talking, reading, listening and writing.

- 3. To recognize ourselves and to create good human relations.**

It is possible to improve our human relations by understanding ourselves and other people. We learn how to make good human relations by using Assertiveness Training, Transactional Analysis and Rational Emotive Behaviour Therapy.

As I mentioned before, by having a realistic attitude to live well with stuttering, we can head for a positive way of living. If a person dreams about life without stuttering, or a person believes his/her life to be a failure, then it is impossible to establish even his identity. Not only for a person who stutters, but for many people, the most important thing is positive feeling about oneself. You are your own person. You are who you are. You are loved no matter what your situation is. Especially with children who stutter, as soon as we notice that a child is worried about his stuttering, we encourage him and tell him that it is O.K. to stutter and to stutter openly.

In closing, I would like to leave you with a quote from Mr. Shinji Ito "I want to ask people who stutter if they have something that they really want to say or anything that they feel they should speak about, other than about the symptoms of stuttering. After all, the most important thing is how we can enrich our lives."

Why we do the things we do?

Deborah Plummer

Senior Lecturer, De Montfort University, Leicester, UK

Deborah is a registered speech and language therapist and imagework practitioner with extensive experience of facilitating groups and working individually with both adults and children who stammer. She currently lectures on topics of health psychology and counselling and is the author of several books on self-esteem and emotion regulation.

When Jim invited me to write an article for this magazine I jumped at the chance and then felt slightly overwhelmed by all the possibilities for content! I hope that the following exploration will be of interest to readers and that it might spark some ideas for future activities within the organisation.

One of my main interests since qualifying as a speech and language therapist some 25 years ago has been the power of the imagination and the ways in which our thoughts can have a profound effect on us physically as well as emotionally. This has included an interest in the neurosciences – what is it that happens inside our brains when we are beset with difficult emotions such as anxiety, and what can we do to help ourselves to regulate these emotions in adulthood?

There is a natural link here with my clinical work, as my clients would often tell me that anxiety played a big part in their relationship with stammering. So what I'd like to focus on for this article is how the brain reacts to stress (this could be general stress or specific stress related to speech difficulties) and how we can use imagery to regain a greater sense of control over the ways in which we handle stressful situations.

A certain amount of stress is of course useful and necessary in our lives. It is one of the factors which motivate us to achieve. Moderate or short-term amounts of stress can enhance memory and learning; coping successfully with a stressful but potentially enjoyable situation can be a tremendous boost to self-esteem; and a quick burst of adrenaline to 'fire up' the body to react to

difficult situations is no bad thing. But when stress is excessive or continuous over a long period of time, even at relatively low levels, then we can set ourselves up for future problems.

The body's natural reaction to stress is based on the primitive need for 'fight' or 'flight' when faced with a dangerous situation. The initial response to a perceived danger is triggered deep inside our brains in the amygdala, two almond-shaped areas (one in each side of the brain) associated with feelings of fear and aggression. The amygdala has been shown to be involved in the laying down of immediate and long lasting emotional memories associated with perceived threat. For example, when a person or object is associated (even by chance) with a traumatic or highly stressful event, the amygdala will produce such a strong neuronal response that a future encounter with that same person or object will trigger the stress response regardless of any actual threat being present. This response is automatic - it bypasses our thinking processes.

Unfortunately, we often prepare ourselves for danger when we don't actually need a physical 'fight' or 'flight' response. Our bodies can be flooded with stress chemicals when we are overly concerned about a job interview, a potentially difficult conversation with a colleague, talking to someone new, or being late for a meeting.

Unlike the primitive reaction to immediate danger, this type of prolonged stress response also involves higher thinking processes and this is where images can play an important role. If you tell yourself to increase your heart rate, or to

sweat you are not likely to notice much response, but if you imagine a stressful or worrying event vividly enough then your body will respond as if that event is actually happening. In this way, if you are anxious about stammering then telling yourself not to stammer is very likely to have the opposite effect because your mind has immediately 'seen' you stammering and your brain's alarm system therefore prepares you for this potentially stressful event, for example by causing your muscles to tense ready for action.

If I am worrying about something over a long period of time or repeatedly imagining myself in stressful situations, then my body will continue to stay ready for action. Eventually I will experience a 'toxic' build up of stress hormones such as cortisol because these hormones are not used up in the intended way. Cortisol plays a part in raising blood glucose levels and in breaking down fat and other proteins to provide extra energy for the fight/flight reaction. However, high levels of cortisol can reduce our memory capacity and ability to learn and will dampen our immune system. This coupled with a repeated fall in levels of dopamine and serotonin (the so called 'feel-good' hormones released in the front part of the brain) can eventually cause us to feel overwhelmed by daily events so that we begin to feel that everything is just 'too difficult'.

It seems very self-destructive to use our imaginations for such negative patterning when positive images are also available to us – even if they might take a bit longer to find! If we become more aware of the images that are informing our lives then we can begin to understand our actions and reactions at a conscious level and so regain a greater sense of control. A sense of control leads to higher self-esteem, which in turn is more likely to result in a greater ability to regulate our emotions successfully. Through constructive use of the imagination we can then face some of our fears and worries and put them more into perspective.

Below are just a few of the many ways in which we can use imagery to help achieve positive outcomes. These are of course only brief

explanations but I hope they will give an idea of the range of possibilities.

In the same way that imagining a stressful event can trigger unwanted stress hormones, imagining yourself in a relaxing environment, where you feel comfortable and safe can cause the release of feel good hormones and induce an increased feeling of calm. This will have a positive effect on breath control and the ability to stay focused on a task.

When faced with a potentially stressful situation you could try out a new 'role' for yourself in your imagination where you see yourself being confident or being more assertive or allowing yourself to stammer in a relaxed way ("What if I had already done this? When I see myself doing this successfully what else is happening? How am I feeling? What can I see/hear? How do I know that things are going well? What did I do that made this go so well? What was the belief/attitude that got me here?").

Imagining that you have already achieved a goal can lead to you performing more successfully. This concept is already widely used by Olympic athletes, who often have a personal imagery coach. These athletes are taught that by imagining themselves performing at their maximum level they can improve their actual performance. In effect, they project themselves forward in time in their imagination and see a positive outcome for a desired goal, experiencing it in their conscious mind and thus creating a memory of the event as if it had already happened.

In order to overcome unwanted feelings of anxiety you could 'reframe' an impending change or worrying event ("If I see this as an interesting challenge, how does my body react? How are my thoughts different? What do I say to myself when I am feeling in control of a situation?").

Imagine what life would be like if you woke up tomorrow and found that overnight a particular worry or stressful situation had resolved. How would your day be different? Imagine yourself waking up and feeling somehow more relaxed or 'in control'. What would you do? How would you

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talk to people? What would you be thinking about instead of the worry? How would other people know that this 'miracle' had happened? Now ask yourself what would happen if you consciously chose to behave 'as if' the miracle had already happened.

What about images to represent stammering? What image do you have of stammering and what image do you have of fluency? I remember one of my clients visualising stammering as a lion – very strong and powerful. He was eventually able to recognise that he could gain control over the lion and that he had a tremendous power of speech despite any stammering. Another saw stammering as an enormous spiky object that constantly hovered in front of him, obstructing his view of the world.

His ability to move the object to one side and 'see' beyond it represented a major turning point for him. For both these people, interacting with their images, finding out more about how they represented their feelings and beliefs at a very deep level, led to them regaining more control in the way that they handled moments of stammering.

The imagination is incredibly powerful. In fact, it can have as much power over us in determining our behaviour as can real events (and sometimes even more so!). As Einstein said, 'Your imagination is your preview of life's coming attractions.' Let's take our imagining seriously and reconstruct the way we'd like to live our lives!

This article has been translated in French by Caroline Martin. Kindly refer to page 46.

Cet article a été traduit en français par Caroline Martin. Veuillez vous référer à la page 46.

A letter to Friends 4 Fluency

Jianliang (Albert) Zhang

Ph.D. candidate and Editor of "One Voice"

Members of Friends 4 fluency,

Thanks Jim Caroopen for inviting me and giving me this chance to share some of my ideas and thoughts with you. First, let me make a short self-introduction. My name is Jianliang Zhang. People call me Albert. I am from China; now, I am working on the Ph.D. degree in communication sciences and disorders in East Carolina University, United States. I have been working with the International Stuttering Association for 5 years as the editor of the newsletter, One Voice. The newsletters can be reached at

<http://stutterisa.org/Newsletters.html#inonevoice>

I have been a stutterer all my life. As a kid, I was a moderate to severe stutterer. There were numerous moments that I could not force myself to utter a sound. In recent years, my stutter has been greatly improved and I think of myself as a mild stutterer nowadays. For many times, I have thought over the possible explanations for my change. Genetics is, of course, a possibility, as we now know that it is involved in the etiology and development of stuttering. I have an uncle who is among the most severe stutterers I have ever seen, but recovered in his 40s or 50s (although it is probable that he just became more adept in substituting words and more confident in himself with his career success). My niece worried my sister with severe blocks 2 years after birth, but recovered in 6 months. However, they might be related just by chance; more evidences are needed to show a clear picture of the role of genetics.

Therapeutic approaches may be another help. When I was young, in China, there was barely any book about stuttering, or any therapy programs for stuttering. I tried reading aloud, tongue twisters, yoga, tai chi, meditation, and others for years, aimlessly. At the age of 20, I learned a little about slow speaking from others; at 30, I became the first user of SpeechEasy, an electronic device, in China; later in the United States, I attended twice the Successful Stuttering Management Program, which focused on desensitization and stuttering modification techniques, and received

from my major advisor, Dr. Joseph Kalinowski, many useful advices. I have to note that SpeechEasy gave me a significant boost in fluency (which motivated me to go to the United States and study under its inventors), desensitization trainings helped to annihilate my anxieties and depressions before and during stuttering, and Dr. Kalinowski instilled in me a deeper understanding of stuttering and its social impact. Because these practices, techniques, device, and advices may have intertwined contributions, it is almost impossible for me to identify a single one that helps the most. It is probably fair to say that everything helps, and the combined effects of them finally changed my fluency.

Aging may be a factor that changes stuttering behaviours. We see that stuttering behaviours change along with the time. Most probably, stuttering is mild during its incipient phase, becomes much worse during adolescence and early adulthood, and stabilizes or even improves at a certain age when one's family and career are established. A recent study by Bricker-Katz, Lincoln, and McCabe (2009) indicated that old stutterers probably have less fear of the social consequences of stuttering, which is understandable with our common sense. I have heard from many that career success improves stuttering. Considering that career success, with a stable job as its least ambitious form, more probably happens to older people, whereas young

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workers have to start from the lowest level of jobs, it is no doubt that young people have more anxieties and depressions, which deteriorate their stuttering.

Probably, differences in stuttering behaviours should be counted. I vaguely remember one American clinician claimed that stutterers with mainly silent blocks, rather than repetitions, prolongations, and secondary behaviours, have a better chance to recover or improve. I definitely heard from Joy Armson, a researcher in Dalhousie University, Canada, that probably people with silent blocks have a better possibility to get benefit from SpeechEasy. These are interesting opinions; however, theoretically and clinically, many difficulties exist. For example, stuttering behaviours change with time and situations and a universal system that subcategorizes stuttering behaviours has not been established.

But I feel that a critical factor that changed my fluency is motivation. I have had a very strong motivation. Growing up in China, I have experienced unspeakable humiliation and shame because of my stuttering. When I was young, people did not know much about stuttering, and they responded to stuttering with instincts or mythical knowledge. Kids laughed at stutterers and bullied them all the time, though actually they laughed at namely all anomalies. Listeners interrupted the stutterer, helped the stutterer to complete the phrase, or showed that “look” that is a combination of shock, pity, disgust, amusement. People did not have a clue about how much their behaviours might hurt the stutterer. Some parents even slapped the kid’s face when stuttering, or asked the kid to eat the tongues of pigs, chickens, or other edible animals, out of good intentions, as according to folklore, that they are “therapeutic” practices. I realized that, under this environment, excluding a few exceptions, being a stutterer means a life without colours, a life characterized with self-inhibition, a life full of pains and struggles. Seeing the dark, desperate future, every day I spent a lot of time and effort to practice speaking, with the hope that soon I would be stutter-free.

I saw the boy next door became fluent in his teenage years, obviously without so many pains and practices. I did not know why things were different for me. For many occasions I felt so helpless, so desperate, that after spending so much effort and time on speaking, I still could not see any improvement. Every time when I had to remain silent, or substitute words, or force a sound to come out of my throat, I felt greatly humiliated, from others, and from my inability to speak as normally as others. So much pride I had in myself, I believed that I should do something great; but I was disheartened by the dysfluency. Years later, when I watched the videos showing photographs of young Dr. Kalinowski with him narrating that when young he prayed to God to take an arm and give him fluency, my eyes were welled with tears: that was exactly the same feeling I had.

I did not surrender. The more humiliations I received, the stronger became my determination. I did not stop practicing. I even decided to enter the major of trading and economics in university. I wanted to become a business person. The main reason was about fluency. With stuttering, the chance to become a success in the business arena is so slim that this decision could be seen as a career suicide. But for, there was no other choice: to speak fluently, or to die.

I did not die, nor did I make myself totally fluent. After four years of college, my fluency was greatly improved, but I still spoke in a manner deemed as slow and “weird” by others. Real life was a big challenge for a stutterer, especially for one whose career success depends on the communication ability. The pains in seeking for a job, looking for a promotion, building social relationships, accumulated to such a degree that I became the first user of SpeechEasy in China. I spent a fortune on that device and I thought that it was the last straw – if it could not help, I probably would not fight any more. Luckily, the device gave me a bright hope in speaking freely, and opened to me the door of a whole new world of scientific research of stuttering.

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What I did not foresee was, even though my fluency was greatly improved with all these therapies, practices, and device, I still needed a few more years and many public speaking practices to eliminate the fears and anxieties before and during moments of stuttering. My fluency ebbed and flew, so was the emotional aspect of stuttering. Nothing I read provided an estimation of how many days, months, and years that I needed to get the freedom of speech. But finally I learned to take it easy and let it come and go (thanks to Success Stuttering Management Program and Dr. Kalinowski). I did remember the moment when, unexpectedly, the anxiety did not show up when I was to speak in a class. I felt like being reborn.

That was not the end. I admit, I still stutter. I still have problems with my home dialect. Even when imagining about talking to people in my hometown, I have that uncomfortable feeling of fumbling and stumbling. It might be worse in reality. But, that is life. Sometimes you have to be tolerant.

I think my motivation is kind of the result of the extremely negative social consequences of stuttering in China, a big pride in myself, and a feeling of responsibility in my behaviours. Per my training related to stuttering, I believe that genetics plays a large part in stuttering, especially

in its etiology, but also probably in prognosis. With my limited knowledge, I have not seen a scientific paper that examines the relationship of motivation and therapeutic efficacy. In fact, I think it is impossible to run such kind of studies, at least now; and if one runs such a study, that might be of poor quality, because motivation fluctuates and is influenced by numerous other activities. And, what one reports of motivation may not be important – motivation is not what one thinks, but must be expressed in one's behaviours. Also, as cynical as I am always, I don't think motivation is sufficient. Because stuttering is such a complex disorder, even with the strongest motivation, one may be still unable to improve.

But I was just stupid enough to spend almost 10 years in a career path that was hopeless in the beginning. I should know that a stutterer should not dream of a career success as a business person – the possibility is as small as winning a jackpot, the cost as high as building a spaceship. It would be much better to get trained as an engineer, an accountant, a mathematician, a programmer, etc., and have a peaceful life, with less intense communication challenges. Now I have gained fluency, and have found peace in my mind, I still don't know if it is worthwhile fighting with stuttering for 30 years. But I don't regret. Life is too short to regret. We just look forward and move on, and fight.

Reminiscences of a New Zealand Speak Easy member

George Dabb

Former President of the Auckland Speak Easy Association

Dear Jim, I decided that the best type of article would be from my own experience in Speak Easy some years ago. Any fluency course is beneficial. The Smooth Speech method has now been superseded by what is called "Naturalness" - an adaptation of Smooth Speech. But the time allotted to the course has been cut to 4-5 days. I consider this too short a time for fluency to get properly established.

My own experience in controlling my stuttering began with an article I saw in the newspaper offering an Intensive Therapy Course at Auckland Hospital. After a lifetime of stuttering, I lost no time in applying. The Course would last two weeks, and for the first week six of us (the maximum number that the Speech Therapist could cope with) lived in at the old nurses' home in the Hospital grounds. The cost was minimal.

It was explained to us that the course was the Smooth Speech method, in which we would need to learn to speak all over again. So we started at 50 syllables a minute, which is a very slow rate indeed, taking a new breath every few seconds and speaking as we were breathing out. We smoothed out the hard consonants so the breathing out would not be interrupted.

We found to our surprise that when speaking at that speed and breathing properly, there was no stutter at all and right from the first hour I knew it was going to work for me.

The first day and a half (12 hours a day) were spent just getting our speech slowed down to that speed, and our breathing controlled and then we gradually increased the speed rate to 100, 150 and 200 syllables a minute until by the end of the first week we were speaking at a normal rate - again without stuttering. Highly elated, we went home for the weekend, but our speech while fluent, was still very fragile. Back on the Monday, we were then given small tape recorders and 35 speaking assignments and sent out into the real world.

These would consist of many situations such as:

- (a) 3 minute conversations with strangers
- (b) Asking directions
- (c) Deliberately stuttering to strangers and then recovering
- (d) Phone conversations with family or friends
- (e) Introductions. These were done at a meeting of family and friends where there was plenty of opportunity
- (f) Speeches

We would report back from time to time for the result of our assignments to be evaluated.

I pretended that my tape recorder was a radio, so that the person I was talking to would not be suspicious as to why I was taping him.

Part way through the second week a public meeting was arranged with nurses being co-opted to be the audience, and each of us would speak to the meeting for about three minutes. We all were very surprised at how well this went. During my search for strangers to have a conversation with, I had the idea of approaching patients in the hospital who were in wheelchairs, on the assumption that they would not be able to run away. They were only too pleased to see me - to tell me all about their operation - and I could not get a word in edgeways. I soon abandoned that idea.

These assignments took us until the end of the week to complete, but we were told that this was only the start of our progress towards fluency. We were advised to join the Speak Easy Association which met every week, and was composed of people like us who had taken an Intensive Course. We did various kinds of speaking exercises, including 2 minute instant speeches, where we were each given a topic, and immediately got up and spoke about it. This teaches us to think on our feet. From there, some of us went out to schools and spoke to the pupils and other organisations. We were so confident we thought we could do anything. Well almost. We had the idea of going on radio, so approached our local community station, and arranged for a time every fortnight for us to go on air. I used the song "Happy Talk" from South Pacific to open and close the programme.

This was a challenge that over 30 members took up. I was compere for about two years, and although members were very nervous when they went into the studio, they came out walking on air. Sadly this programme has lapsed in the last few years, as our members have dwindled. The Hospital courses have ceased as Government funding was cancelled, so eventually a Trust was

formed by Speak Easy members to carry out some treatment for people who stutter. The Trust has limited Government funding and so has to charge for its services, but it now treats mostly children, who respond positively to treatment. We have found that if children are seen early enough, before say, 8 years of age, and before the speech mechanism is fixed in the brain, that almost all become permanently fluent. Adults are not coming forward anywhere so much, so consequently there are very few new members joining Speak Easy.

Many people who took the Course, and became fluent, either did not join Speak Easy, or only stayed for a short time. Most of these gradually lose fluency and revert to stuttering. What we really need after the Course (any kind of fluency course for that matter) is a change of our whole attitude to life. The speaking confidence we achieved during the Course should be built into our life thinking. Then we do not need to think in words as we used to, but to think in ideas as the rest of the population does automatically. If we can do this we will banish our stuttering permanently.

A message to young persons who stutter

Briguel Babet, vice-president of Friends 4 Fluency

I am writing this article to convey a message to young persons who stutter. Stuttering is a problem that must not ruin our life. Life is an adventure which people must appreciate. Some of us think that to speak fluently is the most important thing in life. I would like to disagree with this: everybody can lead his / her life as he / she wishes.

I know that stuttering can cause a very big problem in any human being's life; but there is a ray of hope. For sure, there is somewhere someone ready to help us, to support us, to guide us and to understand us. However, we must be motivated to "get out" of this situation. Indeed, this will not happen by magic but with the effort that we put in.

It is true that fear is present in our life, but fear must not be a barrier to our dreams. We have to rebuild our self esteem and move on. Now that we are young and have plenty of energy, we must not let the problem of stuttering ruin our life. We have to do something about it now, so that later we may enjoy full "freedom". Of course, this will take time, but I know we can do it!

Stuttering Around the Globe

6 Years with the Outreach Working Group of ISA

Stefan Hoffmann

Former Chair of the ISA Outreach Working Group

First, please let me use this occasion to congratulate the Mauritian group for their anniversary and encourage everyone to continue working for the wellbeing of People Who Stutter (PWS) in your country.

Contributing to this festive occasion in – for Germans – exotic and far away Mauritius for me has a special significance. In the dark ages of my stuttering life (from age 12 to 18) I always wanted to run away from the frightening school life in Germany. I watched at maps for hours and looked for the place most far away from Germany: I discovered many places, including Mauritius, but most striking was New Zealand. I started to learn everything about it and became very familiar with most aspects of life there, in my dreams I was there at least once a week, and of course only with being there stuttering was cured that's what I thought.

Since early age I was fascinated by everything to do with foreign countries and languages. Fortunately I didn't let my stuttering prevent me from learning 7 foreign languages and use them. They became a tool for me to meet a lot of people all over the world. I found out that abroad people do care about THAT you try to speak their language rather than HOW you speak. That was always a comfort to me.

Since February 1998 I was involved with the Outreach Program of the International Stuttering Association ISA. I went to the World Congress in Johannesburg / South Africa that year and got really excited. I was elected to the ISA Board, and since then did the "Outreach" efforts there, until stepping back in 2004.

Outreach is the key word. Reaching out to people who stutter is what the national associations and groups do by organizing information campaigns, doing public relations work and so on. At the international level, outreach means to promote the knowledge about stuttering and the idea of self-help worldwide. When you look at the list of countries that are members of the ISA, you can see that still a majority of them belong to the so-called

Western world. But even there we find great differences. In Europe for instance there are more stuttering organizations in the North than in the Southern part of the continent. Obviously, the development of self-help structures and public awareness of a disorder like stuttering is closely linked to the social, political and cultural background of the individual countries. And it must be more than simply the difference between developed and developing countries. After all, states like Portugal and Greece are definitely not developing countries, and treatment of stuttering is available there to some extent. Yet there are no support groups or stuttering associations.

My involvement with ISA Outreach started only 1 year before I left Germany 1999 for a work assignment in – my 2nd home country – China, which is still ongoing despite a break back in Germany from 2003-07. That move to Beijing gave me a huge opportunity to learn first hand about the conditions which stutterers face in a developing country. China can serve as an example to show the chances and challenges ahead for PWS in such countries.

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The situation in actual developing countries is difficult. It is not hard to imagine that in many areas of the world, stuttering therapy does not have high priority in the national health care systems – which is a mild description of the fact that like in China millions of stutterers have to live in societies where there is virtually no knowledge about fluency disorders, and adequate treatment is not or only fragmentarily available. In a way, this is all the more tragic because the self-help concepts existing today represent a cost-effective and easily accessible method of helping people who stutter – or should we say, helping people help themselves.

It is to this background that ISA wanted to put much effort in their outreach activities. In doing so, we want to cooperate with the therapists, as they can play a key role in promoting the self-help philosophy. Many support groups and stuttering organizations have been initiated by therapists and clinicians. Here the International Fluency Association (IFA) with their worldwide membership provides an excellent platform for approaching this target group.

But here again, China is an almost white spot on their World Map. As it was on ISA's until recently. For the reason that I spent time in China from as early as 1993, I have been trying to develop some projects there. In this centrally ruled country with the largest stuttering population in the world, it is most difficult to raise awareness in state institutions, especially as a foreigner. So I tried to contact Chinese stutterers and people with interest in this field (there are no specialized, certified university-educated SLPs in China) and let them learn about Self Help and the benefits. I could see that all think Self Help is a very good idea, but for a long time there was very limited success in finding people who take over the task of "spreading the news". In this country there is still very much of a "consumer's attitude" prevalent, with people expecting any problem can be solved with seeing an expert who does something on them, prescribes a pill and the problem will go without a big effort by oneself. As we might all know, especially with stuttering this will not work in the long run. Parts of the project that were

successful include: editing information material in Chinese, establishing a Chinese Language website, appearance on a National Television health program with 1st time stuttering as subject, find sponsors for these activities. And I am more than happy to have witnessed the birth of several Self Help Groups, some virtual on the web, some with scheduled meetings in cities, over the years since 1999.

Further on, I want to reflect on the cultural differences I encountered while dealing with PWS from such diverse places like Peru, Bangladesh, Singapore, Jamaica and Rwanda. It must be recognized that not only every PWS has a unique stutter, but also almost every country has its own ways of dealing with such problems. Just imagine that even in your own country there are maybe places where people are considered more outgoing (e.g. German South) or more introverted (North) than in others. But at least they still share the same history, language, religion, rituals etc. In both regions of that one country an introduction of the Self Help concept, where you open yourself up to others to a significant degree, may be received with a different response and a group in one region may take more time to get running than in the other region due to that different character of persons.

So similarly, not every therapy or piece of advice is globally valid, considering the vast richness of cultures, traditions, beliefs in our world. This of course makes international cooperation more difficult, time consuming, expensive and prone for misunderstandings. But it also provides a huge pool of ideas and initiatives. So ISA as one of the globally active organisations for stuttering related issues (the other one being IFA) can be the guardian of a huge treasure: the experiences and initiatives of many people with diverse backgrounds and personal histories. It should be kept, nourished and extended. And it would be an asset to have it archived and collected in some way in the future, e.g. in "country files". For sure the story how your group in Mauritius came into existence and Dr. Mark Irwin's role in it would be part of this treasure.

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What does this treasure give to the persons dealing with it every day? Do they feel that they are part of it? Yes, for sure. Being active in the international cooperation of ISA enriches the horizon of the person who is coordinating such work. I can say that before doing Outreach, I did not know about the importance of traditional medicine for curing stuttering in Africa. Or about the opportunities for genetic research in extended African families, with several members stuttering. Or the fabulous success of the Summer Camps for Stuttering Children in Japan, which I could witness myself in 2000. Or issues concerning bilingual stuttering children, that affect my family now as well.

I believe that if I didn't stutter I would not have met so many people from everywhere. It began with attending the meetings of the Cologne SHG in 1991. I learned to come out of the hiding and to talk about stuttering with more or less any person, no matter if he or she is open for that talk or not. I learned that I had missed the 2. World Congress in my home town in 1989. I missed that one !!!!! 15 km from my hiding place there was a World Congress for PWS going on and I did not know it !!!! But I doubt that I would have attended even if I had known about it. I was not prepared. The 7 years in the local group helped me to get ready for Johannesburg '98. So please do not underestimate the importance of the local chapters and groups and their regular activities. Keep them alive and running, that is the best guarantee for ISA's future and that of the World Congresses.

If email had not been invented, the whole Outreach process would be impossible. It was always a huge joy for me to see how I could get in touch with people in, let's say Cameroon and Russia, simultaneously, while myself sitting at home in Beijing/China. Like that we were able to make a lot of resources available to many people.

Today ISA has around 50 member associations in almost as many countries. Through the Outreach efforts we have found Special Friends of ISA in another 40 nations. Those contacts may be stable or sporadic, but they are all possible starting points for groups in those places.

Also, Jim Carroopen was such a contact before, and a group has evolved from it. Especially encouraging are the developments in Africa, which is the real success story of the past decade. It must be hoped that the initiative, engagement and attitude of people like Jim, Joe Lukong (Cameroon) and Moussa Dao (Burkina Faso) will be found also in other places soon. Then the Stuttering Self Help will have a good future and the awareness building process will be stronger than now.

For me personally the involvement with ISA Outreach gave me much fun and excitement, despite the sometimes long hours in front of the computer. It was a good feeling to follow positive events in distant places, knowing that they were partly initiated with support and input from ISA. Sometimes I even could witness the success with my own eyes, e.g. at the World Congress in Ghent 2001 where I met some of the Special Friends for the first time face to face or at the regional Latin American Congress in Buenos Aires in 2002.

There for example I took the opportunity to do my first public speech in Spanish. A big task for me. I love the sound of that language, but I had never dared to look for a chance to present something in Spanish. The way how my speech there came into existence was also funny. I made a draft in English, then had it translated by an internet software, the result proved to be awful, then I was lucky to meet a Chinese who is a translator in Spanish for the Government, his version I emailed over to Peru, where ISA Special Friend Carlos Pimentel Ferrari did the final check. Long live the ISA World Network!!!!

Without ISA I also would not have made my most exciting and frightening experience in public speaking, my largest step outside my comfort zone. In early 2001 (it must have been in a state of craziness) I approached China Television to ask if they want to do a broadcast about stuttering. They surprisingly agreed, but politely insisted that I should be part of the show. Live broadcast, 45 minutes, in Chinese. It went ahead on Feb 21, 2001 and that I managed this challenge successfully is still one of the big miracles of my life. I think

without doing ISA Outreach I would not have come up with such a project.

So from this text spanning some years and many places back to your anniversary in Mauritius.

Be courageous and steadfast in your efforts to promote awareness about stuttering in your local groups, this will eventually also benefit others in distant locations. All the best from China!

Into that heaven of freedom

Dr. Satyendra Srivastava

Coordinator, The Indian Stammering Association (TISA)

*Where the mind is without fear and the head is held high;
Where knowledge is free;
Where the world has not been broken up into fragments by narrow domestic walls;
Where words come out from the depth of truth;
Where tireless striving stretches its arms towards perfection;
Where the clear stream of reason has not lost its way into the
dreary desert sand of dead habit;
Where the mind is led forward by thee into ever-widening thought and action--
Into that heaven of freedom, my Father, let my country awake.*

-- Rabindranath Tagore

When this poem, which is more like a prayer, was written in the early part of the 20th century, many Indians were fighting for political independence. But these soulful words seek something greater and enduring: freedom of mind, of spirit; freedom to live and speak what we truly believe; freedom to seek inner perfection in the outer day to day life. Has India or any country found it, after 100 or more years of these words being written?

Perhaps not. But everywhere we see considerable changes in society: a coloured president in America, more acceptance for lesbian and gay people in society and church, more of interfaith dialogues, greater share for women and people with disability in various spheres of life- and many more people turning away from dogmatic interpretation of the old faiths. In India itself, some trans-gender people (eunuchs) contesting elections for public offices and succeeding, indicates a new consciousness. Of course for every

step forward, society slides back a couple of steps and almost every such 'progress' comes at a terrible price for some individuals, the people who lead the change. Mukhtar Mai of Pakistan is one such example.

Who are these individuals? And how do they come to *this* point, where speaking out becomes not only possible but even an undeniable need? Does it happen to people who stammer (PWS) also? Communal living presents an important phase in the evolution of our consciousness from birth onwards. As children we learn to accept society as an important "given"- an over-riding system. As children we also learn to react in a fixed pattern to various stimuli, arising from within and without. We tend to believe that society is the unchanging and final reality. We develop patterns of coping with our *reality*. These patterns persist over long periods of time because few of us have the

necessary psychological impetus to venture out in to the unknown beyond 'society'.

We suffer, we enjoy and we carry on. A point comes when we are satiated with both suffering and routine joys and look for something beyond. Quite often this is instigated by acute distress and other life changing events. Buddhists, call them *Bardo* moments. One of the scriptures of India, describes similar evolution quite poetically:

"dva suparna sayuja sakhaya..

Two birds of the same plumage- one is seated above, the other below, on the same tree. The lower one tastes sweet and bitter fruits frequently- getting pleased and disgusted alternately. The other one touches none of the fruits, sits calm and serene. Lower one keeps hopping to upper branches. It finally reaches the upper branch and discovers its oneness with the upper bird. There were never two birds. There was always just one bird. Its tasting of fruits too was just an appearance. This realization leads to a state of eternal peace and transcendence (Mundaka Upanishad).

So, pain and suffering are a resource for change. But they must achieve a critical momentum. Then, suffering is no more meaningless, no more personal. Then, it communicates to us a meaning which is universal. We see a sense, a pattern, a purpose behind our suffering. Then, we become open to others' pain and are willing to share our pain with others. Talking about it becomes easy. Suffering is no more a personal storyline- but a bigger plot underlying the cosmos itself.

Five years ago, I was conducting a Training of Trainers (TOT) and was given a little feedback: "You are doing everything fine. But some of your syllables are not very clear." This acted as the last straw and I decided to accept openly that I stammer and to find out what I could do about it. It represented a major departure from the way I had coped with difficulties in my life till then. Only a couple of years later, I realised that this was a *bardo* moment and that I should be happy about it!

With acceptance came insights, release from buried emotions and a lot of psychic energy was free at last for a forward movement. With acceptance came forgiveness too. I forgave myself and the others. This made my attitude and relationship to others very 'light' and full of light. I could talk to anybody now without being defensive or offensive. I could also talk about all the embarrassing moments buried in my psyche for years. I had woken up in the land *Where the mind is without fear and the head is held high*.

In 2008 I met many people like myself, who were on a journey of self realisation. For the first time, my stammering had earned me friends! [The Indian Stammering Association](#) was born soon thereafter. What I had learned to see as my weakness had changed into a strength! I discovered that walking with others on this path was more fun. Seeking fluency for myself alone was a poor idea in comparison. Seeking acceptance in the company of other PWS was a better idea. Together, we could educate our families, friends, employers, colleagues, neighbours. Together, we dreamt of bigger goals.

By the beginning of 2009, we had self help groups in six cities, a vibrant on-line community participating in a blog and a website. Inter-SHG exchange had begun. There are miles to go yet, but when I turn and look back at my own tracks, buried in the sands of fear, shame and lethargy, I realise that what may be just a step for TISA, had been a mighty leap for me. What Tagore wrote was not a prayer, but a prophesy. We are not repeating a prayer, but fulfilling a prophesy, a vision. A vision which we wrote ourselves in past births:

..Into that heaven of freedom, my Father, let my country awake.

My belief system, the way I think and the way I communicate

Keith Boss

Board Member of the British Stammering Association

My dear Friends 4 Fluency in Mauritius, I began my journey in 2006 at the young age of 67. Looking back on my journey of 45 months I will reflect on what I have learned. All these things have changed what I am now, how I think, how my self confidence and self worth have grown but have also helped me to improve my communication skills. These are my reflections about what I have learned which may or may not help you, the reader.

My belief system

When I was born I had a basic instinct within me that I think all of us have. This is 'fight or flee' (FOF). Without knowing it this affected me during most of my life. As I grew up at home, before going to school, I changed in many ways. I learned the way my parents, brothers, sisters and family members behaved towards me so because of FOF I learned their belief systems. I learned to conform to what they thought because if I did not, I was in trouble. This learning and taking on other people's belief systems went on throughout my education at schools and in society. When I reached adulthood and began looking for work I already possessed a set of beliefs (possibly described as well as 'standards') I had absorbed from others. This will probably be true for most of us, including you, the reader.

I have learned in the last 45 months that I had to examine every single belief I held. I looked to see if it was resourceful in 2007/2008 (many old beliefs are not relevant now). If it was not resourceful, I discarded it. This is a very big subject, but here are just three very simple examples of unresourceful beliefs I had. I picked up these three ideas which became beliefs and were with me until 2007. 'Money does not grow on trees' 'It is hard to earn a crust of bread' 'Money is the root of all evil'. These three beliefs led me to think the whole of my life, up to now, that money is very scarce / money is very hard to get / I will have to work very, very hard to feed myself and my family and having a lot of money was a bad thing. I did just that. I worked very hard, doing lots of overtime work to make enough money to care for my family

how I wanted to care for them. (Without knowing it, I focused on what I wanted and made it happen --- more in the next section). But I never looked beyond my family's needs because I did not want the evil of having too much money.

If I look around me today, I see friends and people I know who have worked as I have and have achieved (or not) what I have achieved. I also see people who, for whatever reason do not work, and struggle in their lives. But I also see people who have lots of money. Many, but not all, of those who are very rich always give money away to charities / good causes, or even start their own charities to help others (building schools, hospitals, etc.). This leads me to conclude that money is not evil, but the important thing is what the rich people do with their surplus money.

So here are three beliefs I found to be unresourceful and I have discarded them. I am in the process of learning how to make a lot of money because I intend to start a new Charity.

For people who stammer (PWS) the FOF instinct tends to increase our avoidance patterns. We avoid so much, because we are fleeing from the 'danger' of talking / of stammering. We have created a belief that it is dangerous to talk. I discarded this belief by telling myself 'I will avoid avoidance'. I now know beyond any doubt that it is fun to talk, even if I stammer. I now enjoy talking.

Please note that examining and changing my beliefs did not happen over night. It took 12 to 18 months.

The way I think

I have learned that what I think about often has a way of happening. If I think I want to do something new, usually within a day or so I start to have ideas on how to do it. When I learned how our brains worked, I learned that what we think about we focus on, and what we focus on gets our subconscious brain seeking ways to make it happen. Starting with this as a basic truth made me question how I looked on my stammering. If I think about stammering, I begin to focus on stammering and then, guess what happens. Yes, you are right, my subconscious tries to make it happen because it is helping me to achieve what I focus on.

Another thing I learned, our subconscious brain cannot deal with a negative. This means if my conscious mind thinks about not stammering my subconscious mind has to think about stammering in order to try to obey the conscious minds thought about not stammering. As the subconscious mind is now thinking about / focusing on stammering it tries to help me to stammer, which brings it into conflict with the conscious part of my brain. So there is a mini war going on in my mind between the conscious and subconscious parts of my mind. I am sure a non-stammerer does not have these problems.

Because of this, I no longer deliberately think about stammering, or not stammering. I think of communication and better communication. Here I am thinking of a positive thing and both parts of my brain work in harmony / balance to help me to achieve it. One evening this last week, I was at a concert and after it was over I had the opportunity to speak to some of the ladies in the choir. I noticed that for one brief spell I thought that I must not stammer because they may not understand. Shortly after, I began to gently block. I got back to thinking of communication (more later) and the blocks eased and passed.

Thinking about positive things is a very good for me to make / start new beliefs. I think of what I want to achieve, not what I want to leave behind. (Thinking about what I want to leave behind means I am thinking of it, so will focus on it, so...).

So I do not think, "I want to be fluent", because this has an element of wanting to leave disfluency behind. I think and have a goal of "better communication".

Here is a simple example of this way our brains work. If I ask you not to think of a pink tree, you think of a pink tree and visualise it in order to tell yourself not to think of it. But you have just thought of it. Conflict.

By changing negative thinking into positive thinking I started to improve many aspects of my life, including my communication.

The way I communicate

To enable me to think of communication, I first needed some techniques to help me to speak more easily. This is like the process of using a crutch after a hip or knee replacement. The techniques helped me to regain confidence in talking and to enjoy talking. Once this started I began building up good memories of talking which I thought of when I had difficult periods of talking. I praised myself when talking went well and people understood me. When I had difficulties, I tried to look at why and then to think 'how could I do better'. This kind of process starts an upwards spiral of better talking.

Only humans use words to communicate. This is about 7% of communication. Other species use a variety of sounds. These sounds will be delivered with different tone; volume; pitch and with a tremendous range and variety. This vocal tone can be equated to 38% of human communication. Lastly, all species use body language which makes up the remaining 55% of human communication.

Body language is one of the key parts of communication. When I walk into a room the first thing I do is to look around at the people there and I start to form instant impressions of the people I look at. Similarly people will look at me as I walk in and will see my body language. They assess me without even hearing me speak. First impressions, especially at an interview, or if you see someone you think you like and want to ask them out, are very, very important. Their eyes will be looking at

you and your body language, before you speak. Therefore your body language will either help you, or cause problems.

Do four things:

1. Stand in front of a mirror and look at yourself with happy thoughts in your mind. Look at your body.
2. Now look at yourself with very sad, unhappy thoughts. Observe how your body has changed.

Keep looking at yourself and start again.

3. Stand tall, shoulders back, chin up, very big smile. What are you thinking?
4. Now slump down, shoulders hunched, face hanging down, frowning and almost crying. What different things are you thinking?

These four simple tasks show that how we stand, our body posture, affects how we think. Also how we think affects how we stand. So if I walk into a room with method 3 above people will form one impression of me. People form a different impression of me if I choose to use method 4. I prefer method 3 when meeting new people for the first time and when I am talking or giving a speech (I joined a UK Toastmasters club) or leading a workshop at a conference.

I am not afraid to talk about my stammering to other people. I display confidence and smile and look them in the eye, even if I am stammering. People can be curious and ask questions out of interest. Some will know someone who knows someone who used to stammer, or still does. It can be a good talking point with some people. I usually get good feedback.

Summary

In this article I have talked about 'My belief system', 'The way I think' and 'The way I communicate'. Only a small part of the article talks about stammering. This is because for me the stammering seemed to be less important when I changed my beliefs and the way I thought and communicate. By becoming less important it began to go away. It is still around, but as time passes it will continue to fade into the background. If it disappears, that will be good. If it remains in the background then that will not be a problem.

(In all the above I did not mention my technical meditation, which helps me to an increasing calmness and balance in my life. But this is another tale.)

If you have questions on any of the above please contact me at keithmaxkb@yahoo.com.

Book Review: "Black Swan Green" by David Mitchell

Review by Nell Freudenberger

Sent by Stefan Hoffman; Published: April 16, 2006, the New York Times

Have you heard about the novel "Black Swan Green" written by David Mitchell? I learned about it from a review in the German Stuttering Association Newsletter in 2008. Later last year I ordered that book, and since reading it a few months ago, I see it as one of the best books I found in the last 10 years and in many ways a summary of my life as a stuttering teenager in the 1980's. Many feelings and experiences are described there with words I always felt inside, but was never able to express. This novel is very much able to help educating the general public about stuttering and its effects for PWS in today's society.

Anxious, perhaps, about being mistaken for a supernatural being, Mitchell set himself a different sort of challenge in his brilliant new novel, "Black Swan Green." The book, set almost exclusively in a village of that name in quiet, provincial Worcestershire, follows 13-year-old Jason Taylor through 13 months, each folded into a storylike chapter. This rigid structure provides a certain narrative freedom, and the episodes of Jason's life don't have snug resolutions. Mitchell's storytelling method feels appropriate to adolescence, when each month encompasses so many changes that experience hardly seems contiguous at all.

The challenge here, for Mitchell, is to recreate the sense of wonder of his earlier books in a more parochial setting, on a more intimate scale. It helps that Jason, his hero, has a similar affection for the exotic and otherworldly. He is drawn to the woods beside Black Swan Green, where Gypsies camp in the quarry, an old woman lives in an isolated, fairy-tale house and the ghost of a drowned boy circles the frozen lake on skates. At the same time, he's bound to his family, who live in a new, upper-middle-class development near the village and suffer more ordinary problems. Jason, an aspiring poet, still vividly recalls the stories he heard as a child: his father's office reminds him of Bluebeard's chamber, where visitors wander at their peril. When he asks his talented but stifled mother what's for dinner, she snaps back: "Toad." For a moment, Jason slips into the well of a fairy tale.

"Black Swan Green" is uneventful, at least in comparison with Mitchell's other books. The war in the Falklands briefly intrudes, but is over almost as soon as it begins; Jason understands its import only through the battles between his parents and the endless fighting among his schoolmates: "It's all ranks, being a boy, like the army." Jason exists in the shadowy region of the not-popular-and-not-despised, but his place even there is threatened by a stammer he personifies as "Hangman." When he's alone, an articulate internal monologue replaces the stammer; some of those thoughts are written down in poems he submits to the parish newsletter, which are published under the august pseudonym "Eliot Bolivar."

Anyone who reads Mitchell will start to notice the characters who skip from book to book, remaining themselves but playing different roles. This technique is thematically appropriate to "Black Swan Green," which is concerned with the repetition of language and experience. Madame Eva van Outryve de Crommelynck, an aging Belgian aristocrat who takes an interest in Jason's poetry, was a teenager in "Cloud Atlas." She introduces Jason to a new world of music and literature, including the genius Robert Frobisher (the most memorable character in Mitchell's last novel) and his forgotten "Cloud Atlas Sextet."

"Recurrence is the heart of his music," Madame Crommelynck tells Jason, and the same is obviously true of Mitchell. Short, lyrical sentences

resonate in the novel, building to a kind of refrain. "Birdsong's the thoughts of a wood," Jason thinks, and later: "Music's a wood you walk through." That poetic diction is mixed with the ever-evolving slang of the schoolyard (where using an expression like "ace" or "epic" after its expiration date spells social death). In Jason, Mitchell creates an evocative yet authentically adolescent voice, an achievement even more impressive than the ventriloquism of his earlier books. It's characterized by unusual contractions, and his habit of using nouns as verbs: "Graveyards're sardined with rotting bodies." Occasionally Jason's musings become a little too precociously poetic, but, then, he's that kind of kid.

Jason, left alone for a day, decides to follow Black Swan Green's bridle path to an old Roman tunnel rumoured to be in the Malvern Hills. His walk, a kind of odyssey, takes up an entire chapter: he watches a fight; encounters the girl of his 13-year-old dreams; and spies on a pair of lovers in a field. The real things that happen on the bridle path are hard to distinguish from fantasies: "Here was a prune man in a turquoise smock, about 20 paces up the bridle path." (An escaped inmate from the Malvern asylum, who's stepped into a swarm of bees.) "Here was the dirt-smeared corpse of a boy my age." (His friend Dean, who has hidden in order to scare him.) Dangers pop up like enemies in a video game; Jason's adolescent credulity makes him the perfect narrator for a novel about the line between the fabulous and the real.

Mitchell has, in his previous novels, resorted to farce whenever he writes about England or typically English characters, and I was worried when Jason and Dean stumble out of the woods onto the lawn of the lunatic asylum. (An asylum caper figured prominently in "Cloud Atlas," and even here Mitchell can't resist the shtick of an inmate dressed up in her keeper's uniform.) Almost immediately, however, he curbs his satirical impulse, and this chapter ends with the

madwoman letting out a powerful scream: even if you'd "clambered into the lost tunnel, in that booming hollowness, deep beneath the Malvern Hills, even there, for sure, this tail-chasing wail'll find you, absolutely, even there."

Rather than providing an escape, the magic in "Black Swan Green" eventually intersects with ordinary life. The Gypsies are threatened by bigoted villagers; Madame Crommelynck is deported; and the old woman who scared Jason with the story of the drowned skater moves out of the woods, to a "granny flat" across the road. Her son-in-law tells him that the whole wood is only "two or three footy pitches, tops," as if Jason should've known. And yet it's the granny who helps him understand how he might finally banish Hangman forever. The woods may have gotten smaller, but Jason would stop listening to their music at his peril.

Novelists today sometimes seem a little sanctimonious about the importance of characterization in fiction. Even Mitchell, who takes greater formal and intellectual risks than most of his contemporaries, has said, "Ideas are well and good, but without characters to hang them on, fiction falls limp." It's true that you don't care about a book like "Cloud Atlas" chiefly because it manages to analyze a century and a half of exploitation in societies from Europe to the South Pacific. But as a reader, I don't want to be without the verbal play and inventiveness of the generation that came before Mitchell's. There has got to be a way to write fiction that pays attention to people at the same time that it represents the breadth and complexity of the kinds of societies we live in now. Mitchell is the rare novelist who makes me see that path clearly: it starts among suburban houses, passes through a meadow where boys are fighting, and somewhere up ahead leads into a shrinking wood, populated by ghosts on skates, lunatic beekeepers and Gypsies crouched around a dying fire.

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“Aide-toi et le ciel t’aidera !”

David Victoire

Président de Friends 4 Fluency

Salut à tous ! Enfin un magazine venant de l’île Maurice ! Un début pour certains, un espoir pour d’autres... L’espoir fait vivre chaque homme, et on se demande ce que l’on serait sans espérer des jours meilleurs. L’espoir fait vivre les imbéciles, dit-on ; je suis peut-être un imbécile, mais qui s’en sort très bien aujourd’hui. “Where there is a will, there is a way !” Mais une chose importante : ne jamais brûler les étapes.

Je vais partager avec vous un petit extrait du livre « Tales of Wisdom » du Dr. Awootar. ... *in the manner of a village carpenter who, when asked how long he was in possession of his knife, replied : “Oh, the knife has been in the family for generations. We have changed the handle a few times, and the blade a couple of times, but it is the same knife.”*

Les choses changent avec le temps sans même qu’on s’en rend compte. Ce n’est qu’en y réfléchissant profondément que l’on en prend conscience. La roue tourne, et si chacun de vous veut sortir du bégaiement, qui fait souffrir tant de personnes (1% de la population, c’est-à-dire 60 millions d’humains), vous pouvez le faire. Il faut y croire.

Venons-en à mon expérience. Je suis une personne bègue depuis l’âge de 8 ans. Cela a commencé par des blocages au début d’une phrase, et s’est ensuite aggravé jusqu’à parfois des blocages sur chaque mot. A ce moment, cela a commencé à devenir un calvaire. Pendant 20 ans, je n’avais suivi aucune thérapie, ni même réellement parlé à quelqu’un de ce problème de bégaiement. C’était une souffrance intérieure, qui a fait que petit à petit je me suis éloigné des groupes, et je me faisais de moins en moins d’amis. Je restais scotché sur les gens que je connaissais, et c’était ça mon monde.

En juin 2007, mes parents, et un ami en particulier, m’ont motivé à me joindre au groupe de parole, **Parole d’Espoir**, le seul qui existait à Maurice, et le premier en fait. J’ai rejoint le groupe vers la fin du parcours, et donc cela ne m’a pas beaucoup aidé. Tout change pour moi en mars 2008, avec la venue d’Anne-Marie Simon et d’Aude Fresnay pour le tout premier stage thérapeutique intensif à Maurice.

Ce qui a changé, c’est la façon dont je perçois le bégaiement ; j’ai pris conscience de l’importance de la communication, et de ne plus avoir peur de parler. Les blocages sont inévitables dans certains cas, mais le plus important c’est de faire passer son message, et d’être compris par l’autre. Et à partir de là, tout a commencé à s’améliorer ; les blocages sont devenus de plus en plus rares. Il y a des moments où je parle tellement en société que l’on ne saura jamais que je suis une personne bègue. Il y a même des gens qui ne me croient pas quand je leur dis que je suis une personne qui bégaie !

Le bégaiement n’est pas un problème d’élocution, mais un trouble de la communication. Cela a été la base pour moi, et m’a permis de progresser dans mon cheminement vers la sortie du bégaiement.

Aide-toi, et le ciel t’aidera !

Entretien avec Roseline Bugwondeen, Présidente de l'Association Soutien et Rééducation aux Personnes Bègues

Jim Carooopen

Membre de Friends 4 Fluency

L'objectif du magazine Fluency Island est de recueillir les témoignages et les points de vue de l'ensemble de la "famille des personnes bègues" de l'île Maurice, et dans ce contexte, nous sommes très heureux de la participation de Mme. Roseline Bugwondeen.

Roseline Bugwondeen, qui êtes-vous ?

Je suis une maman de trois enfants, et je suis engagée dans le travail social depuis très longtemps. Je travaille surtout avec les enfants en difficulté ; je suis très touchée par la souffrance des autres. J'ai un enfant qui a une fragilité dans sa parole ; je préfère dire cela, plutôt que de parler de bégaiement. Je n'avais pas abordé le sujet avec lui, et j'attendais qu'il découvre de lui-même qu'il avait un problème. Puis un jour, il est venu me voir en pleurant et m'a dit "Pourquoi je suis comme ça ? Pourquoi je n'arrive pas à parler comme les autres ?" Je lui ai alors dit "Tu n'es pas seul ; on va se battre ensemble, et on trouvera des solutions ! Ensemble, on va faire quelque chose, et on va aussi aider les autres enfants." J'ai aussi vu le désarroi des parents à l'hôpital ENT (hôpital oto-rhino-laryngologique), et c'est de là qu'est partie l'idée de créer une association pour que l'on puisse ensemble parler du bégaiement, et se soutenir mutuellement.

Quels sont les objectifs de l'Association Soutien et Rééducation aux Personnes Bègues ?

A Maurice, le bégaiement est un tabou absolu et les gens ont peur de parler du bégaiement. Les parents qui ont des enfants qui bégaiement ont honte de leurs enfants, et certains d'entre eux ne les laissent même pas sortir pour jouer avec les autres enfants. Notre association est là pour soutenir ces parents qui ne savent plus où aller ; pour les aider à s'en sortir. Nous ne sommes pas là pour nous apitoyer sur le sort des personnes bègues ; les personnes qui ont cette fragilité de la parole sont des gens très forts, et nous leur donnons tout simplement la possibilité de rencontrer des

orthophonistes, de se rencontrer entre eux, et de s'épanouir !

Quels sont vos projets à venir ?

En premier lieu, nous essayons de faire connaître l'Association, pour que les parents et les personnes qui bégaiement sachent qu'il y a un lieu où ils peuvent se rendre pour trouver du réconfort. Puis, avec la collaboration d'une orthophoniste, nous proposons des thérapies de groupe pour les enfants ; nous avons en projet de faire la même chose pour les adultes. Nous proposons aussi des ateliers de musique et de chant à l'intention des enfants et des adultes qui bégaiement, et nous organisons des sorties conviviales pour créer des liens entre personnes bègues et fluentes.

Qu'avez-vous prévu pour la Journée Mondiale du Bégaiement ?

Nous participerons à une émission de télévision pour parler du bégaiement dans le cadre de cette journée mondiale. Nous voulons dire aux gens de ne pas avoir peur, et de ne pas voir honte du bégaiement. [Diffusion le 26.10.2009 à 11h MBC 1]

Avez-vous un message pour les personnes bègues de l'île Maurice ?

La parole nous sert à dire au monde qui nous sommes ; et la personne qui bégaiement n'arrive pas à dire qui elle est, et quand en face d'elle quelqu'un se moque, c'est en effet très dur. J'aimerais dire aux personnes bègues : battez-vous ! Ne baissez pas les bras, et faites en sorte que cette faiblesse devienne une force pour vous ! Ne vous focalisez pas sur ce petit point noir qu'est le bégaiement ; sachez reconnaître vos qualités, et apprenez à vous aimer !

Le bégaiement, ce n'est pas qu'une question technique !

Anne Marie Simon

Orthophoniste et Secrétaire Générale de l'Association Parole Bégaiement

« Le bégaiement, mais ce n'est qu'une question technique ! On bute sur les mots on se bloque, et voilà ! » Ces propos d'un ami reflète l'opinion du public en général et la souffrance qui est attachée à ce trouble de la communication est pour le moins méconnue, et ne provoque aucune réponse des autorités de santé et ni même des chargés d'enseignement auprès des enfants et des jeunes.

Or, le bégaiement peut gâcher une vie et ceci n'est pas seulement vrai en occident : mes voyages en Afrique, à l'île Maurice et dans d'autres pays m'ont appris que cette souffrance existe partout où la parole est plus ou moins importante dans la vie sociale.

Si au départ le bégaiement n'est peut-être qu'un désordre moteur, très vite il devient pour l'enfant, sous le regard des parents et de leur front courroucé, voire leur impatience et leur demande de « bien parler », une gêne, une honte. L'estime de soi va diminuer, ainsi que la confiance en soi. L'interlocuteur du sujet qui bégaié est un juge, un censeur, non plus un partenaire de l'échange.

Bien des hypothèses sur la construction bègue, à savoir comment au fil du temps une personne peut devenir anxieuse face à toute prise de parole, à manquer d'affirmation d'elle-même au point de ne pas avoir une évolution universitaire et professionnelle à l'image de ses compétences. Mais ne pas connaître les causes (étiologie) d'un tel trouble n'empêche pas de savoir comment soulager la souffrance engendrée par ce trouble de la communication.

Quand je suis venue à l'île Maurice avec une autre orthophoniste, Aude Fresnay, pour une semaine de stage thérapeutique intensif, j'ai très fortement ressenti l'implication des participants et leur richesse respective dans des différences pourtant importantes de culture, de religion et de langue

aussi ! Le bégaiement serait-il un trouble qui rassemble en un même mouvement humaniste ceux qui le subissent et ceux qui tentent d'aider ?

Les liens sont restés forts et bientôt nous nous retrouverons ! Pour travailler ensemble, pour faire connaître ce trouble et ses conséquences; car le regard porté par le public et les autorités sur les personnes bègues joue un rôle essentiel. Il faut que soit fait ce qui est nécessaire pour que les petits enfants cessent de bégayer, que les jeunes trouvent une aide et une écoute de leurs parents et de leurs enseignants, et d'adultes qui ne veulent pas pour eux la même galère qu'ils ont subi. (*)

Car personne n'est responsable – a fortiori n'est coupable – de bégayer. Tous ceux qui en sont atteints en souffrent, quelque soit le degré de leurs bégayages. Aussi, la prochaine Journée Mondiale du Bégaiement le 22 octobre, dont le thème est «Être bègue, c'est plus que bégayer » sera l'occasion, j'espère, d'une ouverture vers ce qui constitue d'autant plus un handicap qu'il est mal connu et souvent raillé.

L'Association Parole Bégaiement, par la bouche de sa secrétaire générale, souhaite une belle JMB à tous ses amis.

(*) Vient de paraître «Bégayer : question de parole, question de vie», recueil de témoignages. Publié par l'Harmattan. Il peut être commandé sur le site de l'APB : www.begaiement.org.

Afrique noire, quand tu nous tiens !

Anne Marie Simon

Orthophoniste et Secrétaire Générale de l'Association Parole Bégaiement

Comment tout cela a-t-il commencé, me demande-t-on ? En 1992 probablement, au même moment où je mettais en place l'Association Parole Bégaiement.

Au Bénin

Au Bénin, un projet de développement de la région de Possotomé, à 80 km au Nord Ouest de Cotonou venait aussi de voir le jour : la remarquable vision d'un Béninois, François Houessou, de la possible évolution de 7 villages autour du lac Ahémé comportait successivement la création d'une ferme d'élevage, permettant d'offrir des repas aux enfants des écoles locales (à l'époque 1800 environ), puis d'un centre de nutrition ayant pour but principal de sortir du marasme les petits (dont la mère souvent était morte en accouchant et qui à 3 ans ressemblent à des enfants de 7 mois), puis une Maison des enfants pour 'rattraper' pour ces enfants le développement normal.

Intéresser des donateurs ou acteurs à ce projet n'était pas difficile car on savait où allait l'argent récolté, et on pouvait suivre le développement de ces villages autour du Lac avec précision grâce à l'association ADRP laquelle servait de base arrière, avec l'idée directrice de ne soutenir aucun projet qui n'aurait été décidé par les Béninois en premier.

Il fallait accueillir ceux que le projet intéressait et c'est pendant cette phase hôtelière que l'orthophonie est venue sur les lieux ! Orthophonistes Du Monde (ODM) organisait son Congrès et avec Isabelle Eyoum, orthophoniste, il fut décidé qu'il se tiendrait en **février 2001** à Possotomé.

C'est ainsi que 80 orthophonistes se retrouvèrent dans la palmeraie de l'Hôtel Ahémé. Chacun de nous s'était chargé de matériel pédagogique, de jeux, de jouets et nous eûmes à trier ce que le sable et la culture des lieux ne permettaient pas de laisser aux enfants : comme la pâte à modeler, les

images du Père Castor représentant sèche-cheveux ou Guignol ! Mais la Maison des enfants s'était ainsi enrichie de matériel qui actuellement encore sert aux générations qui s'y succèdent. Il sert en particulier à apprendre le français à ces enfants, avant leur entrée en primaire, sous la conduite de personnes qui se qualifient peu à peu au contact des enfants et des bénévoles occidentaux – la plupart enseignants mais orthophonistes aussi (Patricia Amar et Véronique Thimel) qui vinrent collaborer au projet.

Ce Congrès de 1992 se déroula aussi à Cotonou même, sous la gouverne d'Ortho Bénin qui s'occupait essentiellement d'écoles pour enfants sourds que les congressistes visitèrent longuement.

Je recevais un certain type de leçon d'ODM à cette époque : j'avais accepté, à la demande du professeur de psychiatrie de l'Université de Cotonou, le professeur Hayi, de venir donner une formation sur le bégaiement aux 5 étudiants qui étaient en formation d'orthophoniste. Ce que je ne savais pas, c'est qu'il s'agissait d'une formation privée, et j'ai bien compris avec Brigitte Marcotte, présidente d'ODM alors, qu'accepter de faire ce genre de formation était dédouaner le gouvernement béninois de créer une véritable formation à l'université...

Ce n'est pas à regretter néanmoins car depuis aucune formation n'a été mis en place dans ce pays. Parmi les orthophonistes formés alors, deux sont très actives dans le domaine du bégaiement, en particulier Edith Ouchoumaré qui mène avec le Professeur Gansou l'Association béninoise des personnes bègues et Florence Bada Oladunni dont la présence au Burkina pour la seconde

Conférence Internationale sur le bégaiement à Ouagadougou (Burkina Faso – voir plus loin) était un signe encourageant de son implication dans la sphère du bégaiement.

Plusieurs voyages au Bénin dans le cadre de ce projet me conduisirent à trouver le financement, avec les enseignants retraités de l'Education Nationale, le GREF, d'un projet de formation des enseignants de maternelle, cela apparaissant comme un maillon indispensable avant l'entrée au primaire. Trois années durant, pendant deux périodes de trois mois, des enseignants du GREF (Josette Kerzhero) sont venus former des étudiants adultes, recrutés sur place à la condition d'être bachelier. Ce ne fut pas sans difficultés mais finalement 9 instituteurs étaient opérationnels au bout des trois ans.

Plus tard en **octobre 2004**, revenue à Possotomé pour y voir les amis béninois, pour quelques jours, un soir de visite à Ahémé Sylvie Brignone Raulin et moi même, après avoir fait une semaine de sensibilisation et de formation à Ouagadougou (Burkina Faso, voir plus bas), avons vu venir une dizaine d'adolescents bègues : ayant appris que des spécialistes du bégaiement étaient à Possotomé, ils sont venus spontanément nous interroger sur leur devenir. La plupart avaient quitté l'école à 8 ou 9 ans, ne supportant pas les moqueries des camarades, les sarcasmes des enseignants, dans ces classes où il y a souvent 100 élèves. Ils étaient retournés aux travaux des champs. A 14 -15 ans ils ne savaient ni lire ni écrire et leur intégration au collège, quand ils se décidèrent à retourner à l'école, fut difficile. Nous leur avons proposé une démarche d'information auprès des directeurs des collèges qu'ils fréquentaient. Des documents accompagnés d'une lettre furent envoyés de la part de l'Association Parole Bégaiement. Nous avons regretté de ne pas pouvoir rester plus longtemps pour faire un travail en profondeur dans ce département du Mono.

Au Burkina Faso

Car nous venions de faire un tel travail à Ouagadougou (**novembre 2004**) : une semaine de sensibilisation du public, des enseignants, des

soignants, à l'aide d'émissions de radio et de télé ainsi que de réunions publiques. En particulier une Conférence au Centre Culturel Français avait permis de réunir plus de 200 personnes. Nous avons aidé au développement de l'ACB, Association Vaincre le Bégaiement, que Moussa Dao, pharmacien et personne bègue, avait mis sur pied à la suite de sa participation au troisième Colloque de l'APB à Lyon l'année précédente.

Le soir nous recevions des personnes bègues ou leurs familles, lors de consultation toujours très riches de rencontres mais frustrantes car sans possibilité de suivi. Mais au Burkina l'ACB a bien pris le relais et apporte une aide et un soutien essentiels à tous ceux que le bégaiement fait souffrir.

Au Cameroun

En 2005 ISA, International Stuttering Association qui réunit plus de 41 associations nationales et internationales de personnes bègues, décidait d'organiser la première *Conférence Internationale sur le bégaiement en Afrique à Douala au Cameroun*. Je demandais à ce que cette Conférence soit bilingue car plus de 60% des Camerounais sont francophones. Plusieurs émissions sur RFI m'avaient déjà permis de réunir de nombreuses adresses courrielles de personnes bègues dans toute l'Afrique noire : elles furent informées de cette Conférence. Cela permit, avec le soutien d'ISA, à plus de 15 pays africains d'y être représentés. Des conférenciers thérapeutes et chercheurs venus des Etats Unis, de Grande Bretagne et de France intervinrent à plusieurs reprises et les délégués africains parlèrent de la situation faite aux personnes bègues dans leur pays. La prise de conscience de cette situation fut très forte parmi les participants à cette Conférence : enfants rejetés, battus ; nous n'imaginions pas que parmi les témoignages qui nous seraient donnés, celui de l'Ouganda nous bouleverserait : dans ce pays lorsqu'un enfant n'a pas résolu son bégaiement à 7 ans, il est étouffé rituellement car sa mort doit contenter et réconcilier les esprits avec sa famille !

Je me suis promis alors de faire une *enquête sur les pratiques traditionnelles contre le bégaiement*, ce

que je présentais au 3^{ème} Colloque de l'APB à Lyon en 2006.

Le sentiment dominant pendant cette recherche était que le fait de m'être adressée aux personnes bègues africaines par internet, était un biais important, les réponses ne venant que de citoyens lettrés : les pratiques des villages en brousse ne figureraient pas dans la liste établie ! Néanmoins il fut étonnant de voir qu'à travers tout un continent noir ces pratiques étaient semblables alors que les pays pouvaient être très distants les uns des autres, qu'un front commun à cette « maladie » s'était dessiné au fil du temps et à travers de très différentes ethnies.

J'ai seulement souligné ceci pendant le Colloque et je cite :

« Si la pure description de ces pratiques religieuses est décevante, pour être bien franche je pensais que leur connaissance pouvait apporter un éclairage sur le bégaiement, différent du nôtre certes mais reliant pourtant certaines idées qui sont ou seront évoquées dans ce Colloque : la valeur métaphorique de ces pratiques ne nous renvoie t-elle pas à nos propres convictions sur le défaut de mentalisation de la personne bègue adulte, à savoir que ces pratiques porteraient en elles la possibilité pour un sujet souffrant de bégaiement d'établir un pont entre son monde à lui –exprimé par son bégaiement- et celui de ses ancêtres et divinités auxquels il est rattaché par son nom ? L'imaginaire proposé et porté par ces pratiques permettrait un dialogue intérieur entre soi et le monde des esprits, comparable au dialogue qui s'opère par exemple avec des représentations proposées par le thérapeute - je pense là au travail de Nicole Charpy sur les photos où sont proposées des « rêveries d'un autre monde ». S'il y a eu pour l'enfant africain une insuffisance de langage pour lui permettre la symbolisation nécessaire pour intégrer les interdits de son lignage, de sa famille, ou si l'adulte a transgressé les règles de font-ils lien avec ce passé d'enfant ou d'adulte, pour revenir à son noyau dur ? ».

Plusieurs visites dans les lieux de consultation de guérisseurs (Bénin, Togo et Cameroun) avaient

renforcé chez moi l'idée que lorsqu'on n'appartient pas à une culture et surtout qu'on n'a pas reçu de formation idoine, aucune interprétation des rituels n'est possible, ni permise, peut être sauf ceux qui comme Marcel Griaule ont vécu des années avec les Dogons du Mali. C'est probablement la rencontre avec les guérisseurs qui permettraient de mieux comprendre, en sachant qu'il est difficile –en dehors d'une amitié comme a su s'en créer l'ethno-psychiatre Tobbie Nathan avec des tradipraticiens- de pénétrer dans ce monde d'initiés. J'avais proposé à un professeur de linguistique de Cotonou de lancer un de ses doctorants sur ce sujet des pratiques traditionnelles. Il semble que cela ne fut pas possible.

Il reste attaché à l'animisme beaucoup de peurs et il faudra que d'une certaine façon le bégaiement change de statut dans la société africaine pour que des recherches soient menées. Rappelons qu'en France cette recherche est quasiment inexistante !

Ce premier Congrès eut deux conséquences importantes :

-des associations de personnes bègues furent créées dans les mois qui suivirent dans différents pays (en demander la liste au secrétariat de l'APB si besoin est)
-et ISA lança le projet ISP : International Stuttering Project).

Ce projet vise à envoyer en mission une personne bègue et un thérapeute pour les objectifs suivants :

- 1- Sensibilisation du public à la problématique du bégaiement (radios et télévisions)
- 2- Formation professionnelle de praticiens
- 3- Information des acteurs de la prise en charge du bégaiement
- 4- Echanges et séances d'aide avec des personnes bègues (création de self help/ d'une association).

Deux missions eurent liées menées par Moussa Dao et moi-même au Togo puis au Sénégal.

Au Togo

Cette mission ISP en 2006 faisait suite à l'enseignement sur le bégaiement que j'avais dispensé aux neuf premiers étudiants à l'ENAM, Ecole Nationale des Auxiliaires Médicaux à Lomé en **2004**. C'est grâce à ODM (Agnès Gascoin) en collaboration avec Handicap International (HI) que la création d'un département d'orthophonie dans cette école a vu le jour.

Je retrouvais lors de la mission presque deux ans plus tard ces orthophonistes alors diplômés d'état et pouvais ainsi les aider lors de leurs séances dans les services où ils travaillaient. La mission fut riche de rencontres : grâce à Handicap International et à l'Association des Etudiants et Professionnels de l'Orthophonie du Togo (ASEPOT). Nous avons pu recevoir de nombreuses personnes bègues et des familles, les informer, se faire l'avocat de leur enfant et diffuser des documents auprès de professionnels de la santé et de la psychologie au Togo sur la prise en charge du bégaiement. Des séances d'information pour un groupe d'agents de Réadaptation à Base Communautaire (RBC) sur la souffrance et l'aide possible aux personnes bègues dans leurs communautés rurales furent aussi organisées.

Au total une mission dont la suite se trouvait d'emblée assurée par la présence d'orthophonistes dans le pays. Son déroulement a étonné ceux qui connaissent les difficultés avec le temps que les occidentaux ont en Afrique en général. Tout avait été parfaitement planifié! Le souhait était et est encore le même de voir d'autres pays africains envoyer des étudiants pour cette formation d'orthophoniste; actuellement la nouvelle promotion comporte uniquement deux étudiants non togolais. La formation sur le traitement du bégaiement a été assurée cette année par Sylvie Brignone Raulin.

Au Sénégal

Devant l'efficacité de cette première mission, Moussa et moi-même fûmes envoyés pour une seconde mission au Sénégal en **2007**. Si à Dakar les objectifs étaient les mêmes qu'à Lomé, la mise en œuvre fut très difficile pour trouver un financement complémentaire à celui d'ISA.

Néanmoins, en particulier grâce à l'hospitalité de Julie Vautier, orthophoniste à Dakar et de son mari, nous avons pu, dans des locaux mis à notre disposition par Handicap International (merci à Gilbert Hascouët !) recevoir l'après midi quotidiennement des personnes concernées par le bégaiement ou celui de leur enfant. Le matin était consacré à la formation de quatre orthophonistes, dont trois sénégalais.

Il avait été créé il y a de nombreuses années une association de personnes bègues au Sénégal, mais qui n'a jamais fonctionné. Nous avons rencontré ceux qui l'avaient fondée, lors d'une conférence que nous avons faite à l'ENDSS (Ecole nationale du développement sanitaire et social). Plus de 100 personnes étaient présentes, mais malgré toutes leurs promesses de recréer cette association données à l'Hôpital Fan où se tenait la Conférence, à ce jour rien n'a été fait, ce qui est très décevant.

Cela nous apprend que ce type de mission n'est utile que si une personne bègue sur place prend le projet en main, comme ce fut fait au Burkina (ACB), ou si une organisation s'en charge comme au Togo.

Au Burkina Faso

Au Burkina Faso s'est tenu en octobre –novembre dernier la Seconde Conférence africaine sur le bégaiement.

Grâce au financement offert par ISA et par l'APB, 17 délégués africains se sont retrouvés avec des thérapeutes occidentaux (5) pour un partage chaleureux d'expériences et de connaissances. Une fédération des associations africaines a vu le jour. Trois ministres étaient présents à la cérémonie d'ouverture et il semble que dans ce pays- un des plus pauvres d'Afrique- l'état veuille bien se préoccuper des personnes bègues. Une émission de télévision sur le TV nationale burkinabé nous a permis pendant une heure et demie de parler de la souffrance des personnes bègues, de thérapeutique et d'actions sociales en leur faveur. On voudrait pouvoir en faire autant en France ! Car malgré de nombreuses démarches il m'a été impossible de trouver le financement pour la venue de RFI avec l'équipe de Priorité Santé

pour couvrir cette conférence. RFI est écoutée très largement en Afrique subsaharienne et c'est un grand regret que ce projet n'ait pu aboutir.

A remarquer lors de cette Conférence l'exposé d'étudiantes en orthophonie de Montpellier (OrthoFaso). Elles sont venues pendant deux mois aider dans diverses institutions à Ouagadougou pour le bégaiement et à Bobo Dioulasso pour la surdit . Un projet aussi de faire un  change entre adolescents burkinab  et adolescents franais b gues a retenu toute notre attention.

  la R union

Quatre s minaires de formation, men s par H Vidal Giraud et M Chabert, puis par moi-m me (2004-2007) ont permis   beaucoup d'orthophonistes de prendre en charge le b galement et de soulager des personnes et des familles. Elles sont probablement plus nombreuses   La R union comme en Afrique en g n ral pour des raisons parmi lesquelles le facteur g n tique joue un r le important : le risque d'avoir un enfant qui b gaie est d'autant plus important que le nombre d'enfants est grand.

Un bel ancrage de l'APB dans cette ile (Aude Fresnay) s'est produit   la suite de ces formations et cette antenne s'est montr e tr s active.

  l' le Maurice

Les personnes b gues de l' le Maurice m'ont demand  de venir les voir   cette  poque ; en une journ e des entretiens   la radio et   la t l vision ont permis une sensibilisation certaine du public. A la suite une semaine de stage intensif l'ann e suivante pour sept patients s'est d roul e dans l' le, avec le seul regret que les orthophonistes sur place n'y ont pas particip .

Et demain ?

L'Afrique vous donne tant que le d sir d'y revenir est constant. Mais rien n'est simple quand il manque l'organisation et les financements. Le b galement est m connu dans la plupart des pays. Pour le public en g n ral  tre b gue c'est juste b gayer alors que la souffrance des personnes atteintes de ce trouble peut g cher leur vie. La perception du b galement  volue en France gr ce aux campagnes men es par l'APB et un enseignement qui s'est beaucoup  toff  (s minaires et DU). Il reste pourtant beaucoup   faire. Mais en Afrique subsaharienne il appara t raisonnable de viser avant tout   la cr ation d'associations, de groupes de self help, pour apporter un soulagement. Tout en esp rant que les Etats, lorsque leurs probl mes vitaux (sida, paludisme, malnutrition –et je ne parle pas des conflits !) seront en voie de r solution, pourront assurer la formation de th rapeutes du b galement localement.

Car la souffrance dans l'Afrique noire est bien la m me que celle que nous essayons de soulager ici. Difficult  majeure de communication, ce trouble retentit sur l'insertion sociale et engendre une anxi t  chez les personnes qui en sont atteintes, anxi t  qui se renforce lorsqu'il faut aussi faire face   des probl mes de survie. Nous devons informer, aider, partager, car le b galement est bien un trouble qui fait appel certes   nos connaissances, notre savoir faire, mais aussi   notre part d'humanisme, qu'il est si gratifiant de mettre en  uvre. Les Africains ont aussi beaucoup   nous donner, leur sens de la vie, la g n rosit  de leur accueil. Leurs modes de vie parfois, en particulier en ce qui concerne le temps, nous ont souvent fait r fl chir sur nos propres emplois du temps !

Je me demande : quand vais-je y repartir ?

Témoignage d'un parent

Rudolph Carosin, le papa de Mathieu

Dans une édition du journal *La Vie Catholique*, j'ai trouvé une annonce concernant une réunion d'information sur le bégaiement. La réunion avait lieu au Centre Social Marie-Reine-de-la-Paix à Port Louis. Mon fils Mathieu était une personne bègue. Il avait des problèmes avec ses amis à l'école. Quand son professeur lui posait des questions, il prenait du temps pour répondre, et il se sentait humilié. Parfois il souffre et ses parents avec.

Le jour de la rencontre, ceux qui étaient venus se sont présentés l'un après l'autre. Nous avons pu découvrir la présence d'un couple australien, le Dr. Mark Irwin et sa femme. Le Dr. Irwin nous a expliqué comment il avait surmonté son propre bégaiement.

De ce jour, un groupe de parole a pris naissance sous l'appellation **Parole d'Espoir**. Les membres se réunissaient les samedis après-midi. Mathieu a suivi toutes les sessions, et après un parcours de huit semaines, il est devenu autonome. Il peut parler au téléphone sans problème, il chante et a même rencontré une petite amie.

Je remercie Jim Caroopen pour avoir le courage de travailler avec les personnes bègues. J'encourage les parents qui ont des enfants qui bégaiement à contacter le groupe de parole **Friends 4 Fluency**.

"Les secrets de mes progrès..."

Dev Maulloo, ancien président de Solibeg Fluency Club

J'ai 59 ans, et je suis une personne bègue depuis ma plus tendre enfance. J'ai lutté contre le bégaiement tout au long de ma vie. Pendant tout ce temps, je me considérais comme quelqu'un d'à part, c'est-à-dire, pas comme je devrais l'être. Je vivais ma vie à moi, j'étais très têtu, et je prenais des décisions brusques. Ce que je ressentais était très dur : que des souffrances et de la tristesse.

En 2007, j'ai adhéré au groupe de parole, **Parole d'Espoir**, et en 2008, j'ai suivi un stage thérapeutique intensif à Souillac. Le stage était résidentiel et durait une semaine. Il a été très enrichissant, car avec les nouvelles techniques, j'ai constaté qu'il y a eu des améliorations. Je suis satisfait, et maintenant je peux parler sans peur et sans crainte. Autrefois, j'avais peur de dire mon prénom au téléphone ; mes lèvres tremblaient et j'avais des sueurs.

Maintenant, je vais vous divulguer les secrets de mes progrès. J'accepte mon bégaiement, et dans la mesure du possible, je dis à mon interlocuteur que des fois je bloque dans ma parole. Dans mes moments libres, je choisis des mots et des phrases, et je les répète sans cesse. Je pratique la méditation pendant 10 à 15 minutes tous les jours. Je prends mon temps pour parler, et pour bien prononcer les mots.

Pourquoi nous faisons les choses que nous faisons ?

Deborah Plummer

Chargée de Cours à l'Université de Montfort, Leicester, Royaume Uni

Article traduit de l'anglais par **Caroline Martin**

Deborah est une orthophoniste agréée et praticienne de travaux d'imagerie ayant une grande expérience de groupes de facilitation et de travail individuel avec des adultes et des enfants qui bégaiement. Elle donne des cours en psychologie et en aide psychosociale et elle est l'auteur de plusieurs ouvrages sur l'estime de soi et le bien-être émotionnel.

Quand Jim m'a proposé d'écrire un article pour ce magazine j'ai sauté sur l'occasion, et puis je me suis sentie légèrement submergée par l'éventail des sujets possibles qui s'offraient à moi. J'espère que cette exploration qui suit va intéresser les lecteurs et va susciter des idées au sein de l'organisation pour des projets futurs.

L'un de mes principaux centres d'intérêt depuis que j'ai obtenu mon diplôme d'orthophoniste il y a 25 ans, a été le pouvoir de l'imagination et les façons dont nos pensées peuvent avoir un effet sur nous, aussi bien physiquement qu'émotionnellement. Ceci m'a conduit à m'intéresser aux neurosciences – que se passe-t-il à l'intérieur de notre cerveau quand nous sommes assaillis par des émotions difficiles comme l'anxiété, et que pouvons-nous faire pour nous aider nous-mêmes à réguler ces émotions ?

Il y a ici un lien tout à fait direct avec mon travail clinique, mes patients me disent souvent que l'anxiété a joué une grande part dans leur problème de bégaiement. Voilà pourquoi j'aimerais me concentrer dans cet article à comprendre comment le cerveau réagit au stress (stress général ou stress spécifique liés aux problèmes d'élocution) et comment l'imagination peut être utilisée pour regagner un meilleur contrôle des moyens avec lesquels nous pouvons faire face à des situations stressantes.

Un certain niveau de stress est bien sûr utile et nécessaire dans nos vies. C'est un des facteurs qui nous motive pour nous accomplir. Des niveaux de stress modérés, ou à court terme, peuvent

améliorer la mémoire et l'apprentissage ; faire face avec succès à une situation stressante mais potentiellement agréable peut être un réel stimulant pour la confiance en soi ; et une rapide montée d'adrénaline qui met le corps « en feu » afin de réagir à des situations difficiles n'est pas une mauvaise chose. Mais c'est quand le stress est excessif et en continu sur une longue durée, même à un niveau assez bas, que s'installent les futurs problèmes.

La réaction naturelle du corps au stress est basée sur le besoin primitif de lutter, ou de fuir, quand nous faisons face à une situation dangereuse. La réponse initiale à un danger perçu est déclenchée au fond de notre cerveau dans l'amygdale – deux aires en forme d'amande (situées de chaque côté du cerveau), associée aux sentiments de peur et d'agression. Il a été démontré que l'amygdale joue un rôle dans la mémoire émotionnelle immédiate et à long terme, associées aux menaces ressenties. Par exemple, quand une personne ou un objet est associé (même par hasard) à un événement extrêmement stressant, notre amygdale produit une réponse neuronale telle, qu'une future rencontre avec cette même personne ou ce même objet déclenchera une réaction de stress, quelle que soit la réalité de la menace (vous êtes-vous déjà demandé pourquoi vous bégayez plus quand vous parlez à certaines personnes ? Ceci peut en être l'une des raisons). La réponse est automatique – elle contourne nos processus de pensée.

Malheureusement, nous nous préparons aussi souvent au danger quand nous n'avons pas de réel

besoin de réponse de lutte ou de fuite. Nos corps peuvent être submergés par les effets chimiques du stress quand nous sommes excessivement préoccupés par un entretien d'embauche, une discussion potentielle avec un collègue, parler avec une personne nouvelle ou encore être en retard à un rendez-vous.

A la différence de la réaction primitive au danger immédiat, ce type de réponse prolongée au stress implique un processus de réflexion plus important, et c'est à ce moment là que les images peuvent jouer un grand rôle. Si vous vous dites vous-même d'accélérer les battements de votre cœur, ou de transpirer, il n'y a aucune chance de remarquer une quelconque réaction, mais si vous imaginez une expérience de manière suffisamment réaliste liée à la peur ou à l'inquiétude, alors votre corps va réagir comme si cela arrivait vraiment. Le cerveau n'est pas non plus très bon pour entendre les choses négatives, donc si vous êtes anxieux de bégayer et que vous vous dites de ne pas bégayer, alors il y a des chances d'obtenir l'effet inverse parce que votre cerveau vous a immédiatement « vu » bégayer, et l'alarme de votre cerveau, par conséquent, se prépare pour ce moment stressant, par exemple, vos muscles se tendent pour se préparer à l'action (essayer de ne PAS penser à la dernière fois que vous avez été vraiment bloqué et regarder ce qui se passe !)

Si je m'inquiète de quelque chose pendant une longue durée, ou si je m'imagine de manière répétitive dans des situations stressantes, alors mon corps va continuer à se tenir prêt à réagir. Au bout du compte, je vais éprouver une formation toxique d'hormones du stress telles que le cortisol, car ces hormones ne sont pas utilisées pour ce à quoi elles sont destinées. Le cortisol joue un rôle dans l'augmentation du taux de glucose dans le sang et fait tomber les matières grasses et le taux de protéines afin de fournir de l'énergie pour la réaction de lutte/fuite. Cependant, de forts taux de cortisol peuvent réduire vos capacités de mémorisation, vos aptitudes pour apprendre et peut affaiblir votre système immunitaire. Ceci ajouté aux chutes régulières du taux de dopamine et de sérotonine (les fameuses hormones de bien-être qui sont libérées par la partie avant du

cerveau) peut provoquer le sentiment d'être submergé par des événements quotidiens, et de cette façon, commencer à trouver que tout est juste « trop difficile ».

Il semble très autodestructeur d'utiliser notre imagination pour des motifs aussi négatifs alors que les images positives sont aussi à notre portée – même si cela prend un peu plus de temps pour les trouver ! Si l'on prend conscience des images qui guident notre vie, alors on peut commencer à comprendre sciemment nos actions et nos réactions. On peut apprendre à changer nos modes de pensée de façon à modifier nos réactions physiologiques au stress et regagner un sentiment de contrôle. Ce sentiment de contrôle mène à une plus grande confiance en soi, qui en retour est plus à même de résulter en une plus grande capacité à réguler nos émotions et peut-être de mieux contrôler notre élocution.

Voici maintenant quelques-unes des multiples façons d'utiliser l'imagination pour atteindre des résultats positifs. Ce ne sont, bien entendu, que de brèves explications, mais j'espère qu'elles donneront une idée de l'éventail des possibilités.

De la même manière qu'imaginer un événement stressant peut déclencher des hormones indésirables, s'imaginer soi-même dans un environnement relaxant, où l'on se sent à l'aise et en sécurité, peut libérer des hormones de 'bien-être' et augmenter un sentiment de calme. Ceci aura un effet positif sur le contrôle de notre respiration, et sur notre capacité à rester concentré sur une tâche.

Quand vous êtes face à une situation stressante, vous pouvez essayer un nouveau rôle pour vous-même dans votre imagination, où vous vous voyez en confiance, ou plus sûr de vous, et où vous vous permettez de bégayer d'une façon détendue (demandez-vous « Et si j'avais déjà fait ça ? Quand je me vois réussir à faire ça que se passe-t-il d'autre ? Comment je me sens ? Qu'est-ce que je peux voir/entendre ? Comment sais-je que les choses marchent bien ? Qu'est-ce que j'ai fait pour que les choses aillent bien ? Quelle est l'idée/l'attitude qui m'a conduit jusqu'ici ? »). Le fait

d'imaginer que vous avez atteint votre but, peut vous aider à agir avec succès. Ce concept est déjà largement utilisé par les athlètes Olympiques qui souvent ont un coach personnel imaginaire. Ces athlètes ont appris qu'en s'imaginant exécuter leur sport à leur niveau maximum, ils peuvent améliorer leurs performances personnelles. En fait, ils utilisent leur imagination pour se projeter dans le futur, et voient un résultat positif pour l'objectif recherché, et cette expérience mentale crée une mémoire de l'événement comme si cela était déjà arrivé.

Dans le but de surmonter les sentiments indésirables d'anxiété, vous pouvez changer votre idée d'un changement ou d'un événement inquiétant imminent (si je vois ceci comme un défi intéressant, comment est-ce que mon corps réagit ? Comment mes pensées sont-elles différentes ? Qu'est-ce que je me dis à moi-même quand je me sens contrôler la situation ?). Par exemple, imaginer comment serait la vie si vous vous réveilliez demain et découvriez que pendant la nuit une inquiétude particulière, ou une situation stressante, avait été résolue (ou que vous n'êtes plus inquiet par rapport à votre langage). Comment votre journée serait-elle différente ? Imaginez-vous en train de marcher et vous sentir plus détendu et plus « en contrôle ». Que feriez-vous ? Comment parleriez-vous aux gens ? A quoi penseriez-vous à la place de votre inquiétude ? Comment les gens qui vous connaissent sauraient que ce « miracle » est arrivé ? Maintenant demandez-vous ce qui pourrait se passer demain si vous choisissiez de vivre comme si ce miracle était réellement arrivé...

Quand on construit des motifs d'images de cette façon, on construit aussi une histoire à propos de nous-mêmes, et si l'on se raconte cette histoire souvent, c'est ce qu'on finira par croire profondément.

Qu'en est-il des images pour représenter le bégaiement ? Quelle est l'image que vous avez du bégaiement et quelle est celle que vous avez de l'aisance à l'oral ? Je me rappelle l'un des mes patients qui voyait le bégaiement comme un lion, très fort et puissant. À la fin, il était capable de reconnaître qu'il pouvait prendre contrôle sur le lion et qu'il avait une extraordinaire puissance pour parler en dépit de tout bégaiement. Un autre de mes patients voyait le bégaiement comme un énorme objet pointu qui faisait constamment du sur place devant lui, lui obstruant la vue du monde. Sa capacité de bouger l'objet d'un côté et de voir « au-delà » a représenté une avancée majeure pour lui. Pour ces deux personnes, interagir avec leurs images, en découvrir plus sur la façon dont ils représentent leurs impressions et leurs croyances sur le bégaiement, les ont conduit à regagner plus de contrôle dans la façon dont ils faisaient face au bégaiement.

L'imagination est incroyablement puissante. En fait, elle peut avoir autant d'impact sur nos comportements que de réels événements (et parfois, même plus encore !). Comme le disait Albert Einstein, « Votre imagination est l'avant-première des attraites à venir de la vie ».

Prenons donc notre imagination au sérieux et reconstruisons la façon dont nous aimerions vivre nos vies !

Faisons de notre faiblesse une force !

Durry Pompé

Assistant secrétaire de l'Association Soutien et Rééducation aux Personnes Bègues

Ryan, 15 ans...

Épuisé par le soleil brûlant, il se décide tout de même à emprunter à pied les 4 km de route jusqu'à sa maison, alors qu'il peut très bien prendre le bus...

Le petit Fabrice n'a que 6 ans...

Et pourtant, alors qu'à cet âge, l'école est un endroit amusant, pour lui, y aller est un réel supplice...

Piya, 18 ans...

Très intelligente et aussi très belle. Cependant, alors qu'elle connaît la réponse à la question posée en classe, elle feint ne pas la connaître et garde le silence...

Robert, 42 ans, informaticien...

Ne répond jamais au téléphone. C'est sa femme ou son fils de 11 ans qui y répondent. Quand il est seul, il déconnecte le téléphone, de peur que quelqu'un n'appelle...

Rassurez-vous, Ryan, Fabrice, Piya et Robert sont aussi normaux que vous et moi ! Ils ont tous les quatre, tout simplement, un problème commun : le bégaiement.

En fait, le bégaiement ne les dérange pas moins que la réaction des gens face à cette différence ! A titre d'exemple, Ryan, habitant du Surinam : trébuchant sur les sons qui commencent par 's', il redoute de bégayer en payant le receveur d'autobus. Trop de fois, il en a fait la désagréable expérience, et les gens indiscrets ne cessaient de le dévisager.

Petit Fabrice est en première année au primaire. Il n'arrive pas à se faire des amis car il bégaiement tout en faisant des grimaces. Des parents, visiblement mal informés, ont même interdit à leurs enfants de jouer avec Fabrice, craignant qu'ils ne soient "contaminés".

Piya sait parfaitement que les bonnes réponses données rapporte des points supplémentaires, mais elle préfère se taire au lieu d'être la risée de ses camarades de classe, qui l'épient et attendent le moment où elle bégaiement. Même son prof de

comptabilité lui fait des remarques désobligeantes. Raisons pour lesquelles Piya sèche les cours de comptabilité, au risque d'échouer à ses examens.

Robert redoute de parler au téléphone. Il en a marre d'entendre des remarques telles que, "Dépêche-toi, j'ai pas assez de crédit !", "Faites un effort s'il vous plaît, j'ai pas tout mon temps !", et il préfère éviter tout cela.

Il est clair que le bégaiement fait souffrir, surtout quand on a le sentiment de ne pas pouvoir satisfaire aux exigences... Il s'agit là d'une lutte quotidienne qui fait de la plus simple des tâches, un très lourd fardeau à porter.

Cependant, le but de ce présent article n'est pas de focaliser sur la réaction immature de certaines personnes, ni sur la souffrance que cela engendre ; car uniquement parler des problèmes ne les résout nullement. Or, ces exemples aident à comprendre les craintes de la personne bègue.

Je m'adresse à vous, amis qui avez ce problème de la parole. Je suis aussi des vôtres... de ceux qui

luttent jour après jour... De nombreux facteurs peuvent être à l'origine du bégaiement. Une thérapie peut être efficace chez l'un et ne pas fonctionner chez l'autre. Mais dites-vous bien que pour obtenir des résultats, il est essentiel de poursuivre ses efforts et de rester positif !

Il s'agit essentiellement d'adopter une attitude équilibrée envers les gens, et de ne pas se soucier outre mesure de ce qu'ils pensent de nous et de notre façon de parler. Il est vrai que certains sont désagréables ; ils critiquent, et parfois méprisent même, ceux qui sont différents d'eux.

Elle...

Poème envoyé par Durry

J'ai tant besoin d'elle,
Elle aussi fragile qu'une ficelle...
Je la veux à en mourir,
Bien qu'elle me fait tant souffrir !
Combien l'utilise telle une arme ;
Mais moi, je ne ferais point couler des larmes.
Se laissera-t-elle approcher ?
Me donnera-t-elle une raison d'espérer ?
Elle s'est révélée être une traîtresse,
Car quand j'ai besoin d'elle, elle me laisse dans
la détresse.
Chère amie, je garde espoir que tu reviendras,
Je te serrerai alors très fort dans mes bras !
A cause de toi, les gens ricanent et rigolent,
Mais je t'attendrai toujours patiemment... toi,
ma parole !

Mais soyons réalistes : tout le monde n'est pas ainsi, n'est-ce pas ? Pourquoi permettre aux gens désagréables de vous faire perdre la joie que procure la compagnie des autres ? Si nous laissons quelques expériences malheureuses nous affecter outre mesure, nous ne serons que très malheureux.

Il faut apprendre à vaincre les difficultés du bégaiement pour connaître le bonheur, bien que cela paraisse être une vraie gageure ! Les gens qui méritent d'être vos amis vous apprécieront pour ce que vous êtes vraiment, et non pour ce que

vous avez, ni pour ce que vous pouvez faire pour eux.

Saviez-vous que Moïse, un personnage biblique, n'aimait pas parler en public ? En effet, il avait des difficultés pour s'exprimer. De toute évidence, il a fini par surmonter cette faiblesse.

La cause du bégaiement n'est pas physique. Contrairement à l'idée répandue que "le bégaiement résulte d'un handicap physique, il s'agit souvent d'un blocage mental qui provoque une tension, et la confusion des pensées", explique Watchtower (www.watchtower.org).

Un remède qui m'a beaucoup aidé consiste à lire lentement et à haute voix, puis à s'efforcer de parler de la même façon. Aussi, les exercices et les thérapies de self-help apprises dans le groupe de parole, **Parole d'Espoir**, m'ont aidé. Pourquoi ne pas vous y joindre ? Faire connaissance avec ceux qui rencontrent le même problème, et se heurtent aux mêmes obstacles, peut promouvoir un échange. De plus, il est encourageant de savoir qu'on n'est pas le seul au monde à être dans cette situation. Là au moins, il n'y aura personne pour vous presser à parler, et encore moins pour se moquer de vous !

Cependant, évitez de tomber dans deux extrêmes : le premier consistant à se dire : "Je n'arriverai jamais à surmonter cette faiblesse, je baisse les bras", et le deuxième extrême consistant à se dire : "Je bégaié, c'est mon problème, je n'ai aucun effort à faire, je suis bien comme je suis...". Il est bien de s'accepter comme on est. Mais pourquoi ne pas donner le meilleur de soi pour s'améliorer quand on peut le faire !

Aimez-vous, aidez-vous !!

Comment donc ? En faisant des efforts réguliers et en écoutant les conseils bien intentionnés. Tout comme on risque davantage de tomber en courant qu'en marchant, de même, on risque plus de trébucher en parlant vite. De plus, les "euh", "hem" sont très fréquents chez les personnes bégues. Evitez-les autant que possible.

“Continuez à parler lentement jusqu'à ce que votre bégaiement diminue. Ensuite, vous pourrez augmenter graduellement le rythme de votre élocution” conseille la revue Watchtower. Fréquentez ceux qui souhaitent que vous vainquez votre faiblesse. Aussi, apprenez à ne pas vous prendre trop au sérieux, et même à rire de vos propres faiblesses.

Par exemple, un jeune homme qui a de grandes oreilles disait en riant qu'à sa naissance, ses parents ne savaient pas s'il allait marcher ou voler ! Il ne se complexait pas outre mesure. Vous aussi de même, ne faites pas de votre bégaiement une montagne. Vous vous détendrez en faisant preuve d'humour. Rappelez-vous que les taquinerie ne sont pas forcément méchantes. Un proverbe allemand dit que “les petits démêlés entretiennent l'amour.”

Il vous sera ainsi sans doute très utile de consulter un spécialiste, tel un orthophoniste. Ce dernier vous donnera sûrement des bons conseils pour réussir à vaincre, et à vivre avec le bégaiement. Les bons conseils sont tous bons à entendre, mais le plus dur est de commencer. Vous ne pourrez jamais apprendre à nager si vous avez peur de

vous mouiller !! De même, il vous sera difficile de vaincre votre faiblesse si vous n'êtes pas disposés à faire l'effort de vous libérer en prenant, par exemple, l'initiative d'une conversation, en faisant comme nous l'avons appris dans le groupe de parole, **Parole d'Espoir** ; en faisant la connaissance des autres, ou en participant à des activités de groupe.

Sachez aussi remarquer vos progrès ! Ne vous abaissez jamais ! Ce n'est sûrement pas un défaut de parole qui diminue la valeur d'une personne ! Faites-vous des rechutes fréquentes ? Saisissez donc l'occasion de reculer pour mieux sauter !

Avez-vous parfois le sentiment que personne ne se soucie de vous, ou de votre situation ? Je voudrais alors partager avec vous la pensée qui m'encourage le plus. Un livre sacré, la Bible elle-même, parle du bègue, du dessein de plus grand personnage de l'univers, Dieu :

“La langue du bègue se déliera”, “La langue des bègues sera prompt à dire des choses claires !” (Esaïe, ch. 32 v. 4).

Bon courage et bonne continuation, chers compagnons !

Le bégaiement est un frein qui démolit le rêve de sa victime.

Balram Appadu, membre de Friends 4 Fluency

J'ai 56 ans, je suis marié et père de deux filles. Dès l'âge de 4 ans, j'ai commencé à bégayer lorsque je prenais la parole. J'avais peur de parler avec les autres, car je craignais de bégayer. Au collège, quand on faisait la lecture à haute voix, je redoutais beaucoup que mon tour arrive. Au travail, j'évitais de participer à des discussions avec mes collègues.

En mars 2007, j'ai rencontré le groupe de parole, **Parole d'Espoir**, grâce à une annonce parue dans le journal *Le Défi Plus*. J'ai ainsi participé à plusieurs exercices pour améliorer ma parole. Puis, en mars 2008, j'ai pris part à un stage thérapeutique intensif organisé par **Friends 4 Fluency**. Je remercie les orthophonistes Anne Marie Simon et Aude Fresnay pour leur inestimable encouragement.

Quand j'ai un discours à préparer, j'ai toujours tendance à le remettre à plus tard. J'éprouve de la colère et de la frustration quand je n'arrive pas à dire ce que je veux. J'aimerais me taire, ou même parfois mourir, plutôt que de bégayer.