



MUSTEL GROUP
MARKET RESEARCH

Awareness and Perceptions of Epilepsy - Top Line Report

September 2007

Presented to:

BC Epilepsy Society

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Foreword

Background and Objectives

At the request of the BC Epilepsy Society, Mustel Group conducted a qualitative research project in September 2007.

The objectives of the research were as follows:

- ▶ to gain a sense of the level of awareness and knowledge of epilepsy amongst members of the target groups
- ▶ to understand any stigma that is associated with epilepsy
- ▶ to understand the perceived barriers to hiring a person living with epilepsy
- ▶ to determine the common myths about epilepsy
- ▶ to gain a sense of the facts that have the most positive impact on perceptions of epilepsy.

Methodology and Respondent Selection

A series of two focus groups were conducted in a boardroom setting, each group consisting of six individuals. The groups were moderated by Ms. Kathleen Roach of Mustel Group and were audio-taped.

The groups were broken down as follows:

Group 1	General population Spread of ages and incomes Mix of ethnicities
Group 2	Employers or persons responsible for hiring Small- to medium-sized businesses Mix of business types

The Findings

1. General Discussion of Epilepsy

In the discussion of epilepsy, the groups were first asked what their top-of-mind associations are when they hear the term.

Most of these respondents, with the exception of a few who had some knowledge of epilepsy, immediately think of major convulsions.

Throughout this discussion it became clear that the majority of these respondents see epilepsy as something major and that their fear comes from a lack of knowledge regarding what to do when a person is having a convulsion. Additional fear is associated with the fact that a seizure can occur without warning, which does not allow a witness to prepare for handling the seizure.

Another consistent association with epilepsy is the concern that the person having a convulsion can swallow their tongue, thus cutting off their airway, and possibly die. Many people suggested that it is important to put a spoon in the mouth of a person having a convulsion to prevent them from swallowing or biting their tongue. A couple suggested that it is important to put the person on their side while they are having an episode so that they are less likely to block their airway.

One person also suggested that it is valuable to give a person some warm sugared water after they have had an episode.

When asked what epilepsy is, most did not know. Some associate it with the brain and see it as a malfunction that occurs from time to time. Others did not know anything about it and were not at all sure whether it happens randomly or if there is a trigger that can bring on a seizure.

2. Imagery

Respondents were given a deck of abstract images and asked to select images that reflect their sense of epilepsy.

Images like a guy drowning in paper were selected to indicate the chaos that they associate with epilepsy. Another image chosen by individuals in both groups was a series of signs pointing in different directions, again suggesting chaos and a lack of control.

The image of a baby between two statues was chosen as a reminder that people can sometimes be cruel to someone with epilepsy, teasing them about the fact that they have seizures and perhaps suggesting that they lack control. This individual felt that a person living with epilepsy is likely very sensitive and needs to be cared for.

One respondent who had known someone with epilepsy was aware that it was possible to have a very minor episode. That person chose an image of a latex fist, suggesting the softer, less threatening aspect of epilepsy.

Overall, with the exception of a couple of people who had direct knowledge of epilepsy and therefore were aware that there is a wide range of possible episodes, most of these respondents associate epilepsy only with major convulsions and total lack of control.

3. Hiring a Person with Epilepsy

Both groups were asked to imagine that they were going to hire someone for a project or a job and that the person they had selected as the best qualified divulges that they live with epilepsy.

The reaction from the non-employer group was similar to that from the group of employers. The first thought that most respondents had was fear that the person would have a convulsion while on the job. For individuals in the general population group, there was fear associated with the possibility that they might have to “deal with it”. Some in the employer group were concerned about insurance and liability.

Everyone said they would not dismiss the idea of hiring the person, but they all felt it would be important to get more information. Some thought they would likely ask about the frequency of the episodes, another wanted to be able to contact previous employers to determine if there had been any problems associated with the epilepsy.

One employer suggested that the other people who would be working with that person should be made aware of the fact that he or she has epilepsy. Others felt the opposite, seeing it as something that should not be divulged unless the individual living with epilepsy decided to do so themselves.

Some also said there were jobs for which they would not hire a person living with epilepsy. Operating heavy duty equipment, for example, seemed like a dangerous thing for a person with epilepsy to be doing. Roofing was another occupation that some felt might not be a good idea in case the person had a convulsion while on the roof.

Throughout this discussion it was clear that there is a tremendous lack of knowledge amongst all but a few of these individuals regarding the frequency and scope of epileptic episodes. There is also a lack of knowledge as to what to do when a person is having an episode. Hiring a person who lives with epilepsy is acceptable to most, depending on the position they will be filling. The individuals with epilepsy would not be hired for any occupations that might result in harm if the person had a convulsion on the job.

4. Myths and Facts

The following myths and facts were presented to the groups for reaction.

Myth: A person who is having a convulsive seizure can swallow his/her tongue.

Response to this statement was that it is true. Someone suggested that it might be “an old wives tale” but everyone agreed that this is appropriate action when someone is convulsing. As indicated in the opening discussion the belief is associated with keeping the airway open so the person can breathe. It is seen as a life-saving act.

Fact: It is impossible to swallow your tongue. If you are with a person who is seizing, stay calm, time the seizure, move anything that they might hurt themselves on, and do not restrain them. Never put anything in a person’s mouth during or immediately after a seizure.

This fact was clearly a major surprise to everyone. For most people it was a relief to know that they should do nothing except clear the area and wait. Some of the fear around epilepsy has to do with the idea of actually having to do something about it. Knowing that there is nothing to be done except to let it pass and protect the person from hurting themselves relieves the witness from a feeling of responsibility and the fear that they might do the wrong thing and harm the person.

Also, this statement acts as a reminder that a seizure is temporary and does pass. For some of these respondents, this diminished their sense of its severity.

Myth: People with epilepsy cannot drive.

Many people believed this to be true. Because a seizure is seen as something that comes on suddenly and without warning, and because seizures are seen as strong and debilitating, most agreed that it would be dangerous for a person living with epilepsy to drive.

Fact: If a person’s seizures are controlled for six months or more, with consultation from their doctor, they are free to drive.

This statement made many respondents feel that epilepsy can be controlled. It thereby diminished their fear of being around a person living with epilepsy who might have a seizure in their presence.

Myth: All seizures are convulsions.

Most people believed this to be true. The few people who actually know someone living with epilepsy knew this to be false, but all others associate epilepsy with convulsive seizures.

Fact: There are over 40 kinds of seizures ranging from convulsive limb movement to speech problems to blank stares, depending on the part of the brain affected by the epilepsy.

The fact that there is such a broad spectrum of epileptic episodes was important for almost everyone in diminishing their sense of the severity of epilepsy. This led many to suggest that if they were interviewing someone for a job who indicated that they live with epilepsy, they would likely ask what type of episode they have experienced and decide what jobs they could or could not do based on that.

There was still a fear from a few employers about liability. Even if the person indicated that they had very mild episodes, these individuals would still want to check with their insurance company before hiring that person.

Overall, though, this statement had a very positive impact on most individuals regarding their sense of epilepsy.

Myth: Epilepsy is rare.

There were mixed responses to this statement, with some agreeing that it is fairly rare and others suggesting that it is not so rare. When asked what "rare" actually means, however, there were equally mixed responses.

Fact: One out of every 100 Canadians has epilepsy and lives with seizures. With medication, good general health and public education they may work, drive, have families, go to school and live the lives they want to live.

This statement, by itself, did not particularly change the way these individuals see epilepsy. When combined with the statement that indicates the scope of types of seizures, however, many people began to think that they might know someone with epilepsy and may not have realized it. Knowing that epilepsy is common and can manifest in subtle ways definitely changed the way these individuals view epilepsy. The two statements together also alleviated much of the fear that is associated with epilepsy.

5. Summary

At the start of the sessions, most respondents expressed a sense that epilepsy is severe and debilitating in that it comes on without warning. That fear was compounded by the majority having little or no knowledge of what to do when someone is having convulsions.

By the end of the sessions, respondents all felt quite differently about epilepsy, primarily because they were now aware of how common it is and how subtly it can manifest. The other important piece of information for these groups was the fact that they do not have to take responsibility for the person who is convulsing, other than to clear the space around them and let them go through it.

Most agreed that there is very little information readily available about epilepsy. Those in the workplace who do hiring often receive material and information about many other ailments like diabetes but not about epilepsy. If they were sent information of the nature provided in these sessions, hiring a person living with epilepsy would be much less an issue than they had felt at the beginning of these sessions.