

FIRST PART = Commentary

SECOND PART = Caregiver services, statistics and remarks from clients

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CAREGIVERS MUST LEARN TO DANCE IN THE RAIN

If you are taking care of an elderly relative (father, mother, husband or wife) who is losing their autonomy and are depending more and more on you to help take care of them on a regular basis, you are considered a natural caregiver as opposed to a paid caregiver. In other words, you are not being remunerated for your moral support, service and financial assistance. Regardless of whether your elderly loved one lives with you, are on their own or in a special residence for the elderly, you are still helping to care for them. Whether you are elderly yourself; have a family to take care of, are working, or both, you are no doubt exhausted, stressed, most of the time and sometimes panicked, while trying to keep up with all your responsibilities. Perhaps your loved one has Parkinson's or Alzheimer's. You may be communicating or dealing with paid caregivers, or perhaps you are trying to manage everything yourself: scheduling and accompanying your loved one to their medical appointments, preparing their meals, running errands, assisting with their bath and personal hygiene, managing their banking matters and much more! You are probably feeling quite overwhelmed and that you, yourself, need help and information about resources that are available to you and your loved one, you are probably feeling that you need a break, some time off to recuperate.

As friends and most family members of the elderly slowly disappear because the person they once knew is no longer "there" (in a manner of speaking), the natural caregiver becomes inevitably "trapped" into being the sole caregiver. Without the necessary resources and information to help them deal with their elder's disease or situation, without realistic expectations with respect to their situation, they feel discouraged, too stressed and too alone to keep up with their social life and therefore, isolate themselves. They lose perspective and blame themselves when things go wrong or when their elderly loved one does not cooperate. Caregivers usually become the hidden or not so obvious victims, they make sacrifices no one sees or recognizes and if they do not ask for help, as a result, they often become ill as well!

It is important though, to know that you are definitely not alone! Not only are there many caregivers out there, such as yourself, increasing in number as the Baby Boomer generation ages, but there are a variety of resources and services to tap into as well. This is why it is important to seek help through a community organization or a CLSC to guide you through the various steps involved. As the elderly who need care increase in numbers, it will be impossible for the health care system to assume total care of everyone. Natural caregivers will be in great demand. Natural caregivers can be young or old. Rosalynn Eleanor Smith Carter, who served as First Lady (between 1977 – 1981) and spouse of the 39th President of the United States, Jimmy Carter, very correctly stated,

“There are ONLY FOUR kinds of people in the world: those who HAVE BEEN CAREGIVERS, those who are CURRENTLY CAREGIVERS, those who WILL BE CAREGIVERS and those who WILL NEED CAREGIVERS”.

The interesting thing about this quote is that, it tells us that caregiving is all around us, part of everyone’s life, that caregiving is cyclical and almost all of us will most probably experience, first-hand, being each type of the four kinds of people, described in the First Lady’s model, over the course of our lives.

Most people, are not prepared for giving appropriate care, let alone quality care. What needs to be done is for community organizations such as SSHQ-Hellenic Social Services of Quebec, to reach as many soon-to-be-caregivers early enough and to empower them, so that they do not feel like trapped victims but rather, skilled, comfortable and happy caregivers of the elderly.

The other important concept that needs to be addressed in more detail is open, honest, quality communication and respect for the loved ones being cared for. If you generally feel love and respect for other human beings, including yourself, this will not be difficult for you. Caregivers have to learn to ask for help and to not feel guilty about asking for help for themselves, because if they are not well, the elderly requiring help will not be well either. An important element to remember is not to panic when faced with stress or difficulty. Love, respect and patience are necessary and these have to come from within the caregiver first. In support of this concept, imagine the scenario of a mother and her two toddlers being in a dangerous airplane situation where the passengers are asked to put on the oxygen masks located above their seats. It would make perfect sense for the mother to put her oxygen mask on first and then put the masks on her children and not the other way around. She has to guarantee her well being first, in order to be in a state where she can help her children through the subsequent steps. This same mother in normal circumstances has to raise her children with patience and understanding and not get upset if the children ask the same question many times or if they ask too many questions. She has to choose her words wisely in order to encourage them to learn and to grow. Frederick Douglass, a writer and social reformer, quotes,

“It is easier to build up a child than to repair an adult, so choose your words wisely.”

Choosing words wisely, can be an ideal that we can strive for all the time, we should feel love and respect towards ourselves and others, what is good for the children of the world, should be good for an elderly person with Alzheimer’s. Therefore, if a caregiver has access to training, information, support groups, communication skills training for dealing with the Alzheimer patient, day center services for their elderly loved one, respite services for themselves, then the caregiver will be strong, confident, happy and healthy and will in turn help the elderly who is being cared for to be confident and happy. Simply put, the caregiver can be guided by the three (3) B’s of caregiving,

“Be prepared, be honest and be well!”

Once the caregiver is empowered with the appropriate information and skills, the stress level of the caregiver will gradually diminish. A lot of people also turn to Yoga or exercise to control their level of stress. They try to channel negative stress into positive energy. We have heard these scenarios before. It is not looking at the glass as being half empty, but to look at it as being half full. It is not about waiting for the storm to pass, it is about learning to dance IN the rain. For example, a caregiver who really wants to be of help to an elderly afflicted with Alzheimer's or Parkinson's disease, will not dwell on the disease but rather value the quality of the interaction, each moment spent together, adding to the list of good times, having good conversations, doing things together, talking about feelings, listening to music, etc. there is no right or wrong, just positive activities. Of course this will take practice, trial and error. The important thing is to want to be positive. Some useful things to say as a caregiver: I am with you in this, You can count on me, How are you holding up?, How can I be of help? Let's go for a walk. Thomas Chandler, had the right idea, as a Canadian politician, judge and author (1796-1865) he quotes,

"To love a person is to learn the song that is in their heart and sing it to them when they have forgotten."

This is a work in progress, but not impossible to master, with respect, patience and love for our fellow man.

*On a similar note (pardon the pun), while on the theme of song and music, what comes to mind is the documentary, "**Alive Inside.**" If not for the persistence, patience, love and respect of social worker, Dan Cohen for elderly living with Dementia, he would not have discovered that music therapy brings back specific memories and moments of happiness to the Dementia patient when songs and music are played that were significant to the patient when they were young adults.*

Mother Theresa would definitely support the above, as she was often quoted as saying that,

"It is not how much you do, but how much LOVE you put in the DOING, that is important."

Therefore, even though not all of us can do great things, or have the time to do them, we can surely do small things with great love for others! Even a few minutes of your time can go a long way, to the individual who needs care, who used to be as successful as we are, it can turn things around for them. We should not underestimate the power of a kind word, a smile, an honest compliment, a listening ear.

II. PART TWO

SSHQ---EMPOWERMENT SERVICES TO NATURAL CAREGIVERS OF THE ELDERLY:

We offer individual consultation, information and support to caregivers of the elderly who live in Laval. Our intervention counselors have received intensive training on the subject of Alzheimer disease. We continue to sensitize the Greek community to the needs of natural caregivers of the elderly. We do this through the media, conferences and pamphlet distribution. Our goal is to reach as many natural caregivers who are helping a loved one afflicted with Alzheimer's or Parkinson's (etc) as we can before they burn out.

The client of SSHQ is important. They have to feel welcome, they must be treated with respect and they must be involved in their personalized intervention that we will provide. We have to do our best to empower them, so they can maintain their dignity while going through all of their life changes and so their quality of life is always up to par. We have to help them address their psychosocial needs. Our priority is to empower the caregiver with knowledge and skills in order to improve his or her approach and interaction with their loved one.

The caregiver has a variety of support services to participate in that are offered during the day, evening, or weekends in order to facilitate the caregiver's schedule. These activities range from follow up calls, individual consultation and active listening, support groups, monthly thematic workshops, conferences, information on public and private home-care services, respite care.

The conferences on ***Elderly Mistreatment Prevention, Parkinson's, Alzheimer's, Stress Management, Grief Management, Demystification of Mental Health, Mandates Of Incapacity, When Placement Should Be Considered and the Different Types Of Residences, How To Prevent Falls, How To Encourage Your Loved One To Eat Nutritious Snacks***, to name a few, were attended with record numbers of caregivers. During the year, we also offered support groups in either English or Greek, where professionals (male and female) sons and daughter caregivers of elderly attended, in addition to primarily Greek speaking spouses of ill elderly who were being taken care of. In both type of groups, the results were very good, participants were quite satisfied and reported more reassurance in their roles as family member caregivers by the end of the six-week program.

SOME STATISTICS

We estimate that there are approximately **7000 natural Greek caregivers in Laval** that should be reached. Our natural caregiver, active, client dossiers have tripled since we started the program (approx.. 150 dossiers).

35% of these caregivers are spouses, **53%** are sons or daughters, **3%** are grandchildren, **2%** are brothers or sisters, **1%** are close friends and **6%** have another relation with the elderly that they are helping. While we have documented about **201** caregivers who have called or visited us in the last year, to whom we have offered about **326** hours of in-office consultation and psycho-social support. It is also important to note that **a small number of our caregiver clients are from outside Quebec**. Such as in other provinces, the States or in Greece.

We ran **four support groups** of approximately **9** caregivers in each, very successfully, guided by our intervention counselors and a variety of invited professionals depending on the topic. Two of these support groups were held in Greek (frequented mostly by spouses) and two in English (frequented mostly by daughters or sons). We also observed that the average age of women in our spouse-support groups is **70**, while for men it is **81** years of age.

The majority of the elderly who are being helped by our natural caregiver clients have Alzheimer's, Parkinson's or Down's syndrome. **45%** have serious mobility issues, muscular dystrophies, schizophrenia, stroke, depression, blindness, and cancer or require regular kidney dialysis treatment.

Many inform us that the public system is simply not helping their situation, there is an absence of necessary home care support. More sensitization, promotion and respite care in the form of a day center for the elderly is an absolute necessity in the community as there are waiting lists to get respite assessment and for respite services, also, because of language and cultural barriers, many of our caregiver clients or their elderly loved one, have not been helped and the referrals bounce back to us. The evaluations that are filled by participants after each activity, illustrate a high satisfaction for the content, our employees and animators.

An interesting note to make at this point is that there are approx. 37% male caregivers who participate at our activities.

We are funded by APPUI LAVAL. Our budget for this program is \$40,000. however, at least double that amount is required to meet the caregiver needs of our community.

CLIENT REMARKS REGARDING OUR PROGRAM

"The workshops have made me a better caregiver!"

"The support groups helped me deal with each one of my problems with patience, perseverance and new skills that I learned."

"I really appreciated the activities and I also made friends!"

"I take better care of myself, I take the time that I need, without feeling guilty, nor judged!"

"The program added positive influences in my life!"

"The themes of the discussions are pertinent to my situation."

"I now have a better understanding of the public and community resources available to me."

"I have learned new skills, thanks to the training and the attentive and knowledgeable instructor."

"Thank you for all your help, I no longer feel that I am dealing with this alone!"

"My physical health has greatly improved because of your program!"

HOW WE REACH OUR CAREGIVER CLIENTS

By mail, telephone, announcements in the local media, through other HCGM services, Hellenic Medical Association of Qc, the CLSCs, word-of-mouth