

By Tewentahawih'tha' Cole
Health Educator of the Saint Regis Mohawk Tribe,
Office for the Aging

“One day, my father went from being in the best of health to needing 24-hour care. He suffered a brain bleed and needed to be hospitalized. During that stay at the hospital, we found out his brain bleed was due to an undiagnosed brain tumor. Testing was done, we found out it was terminal cancer. After a period of rehabilitation, we brought my Dad home.

My mother provided the majority of his daily care and needs including: bathing, dressing, toileting, etc. We kids chipped in anytime we could. After a while, we started noticing issues. Because my Dad took care of the bills, the health insurance, the maintenance on the car, and the household repairs, things were starting to fall apart. We got home one day and the electricity was off because the bill hadn't been paid. My mother had stashed away a pile of insurance papers because she had no idea what to do with them. And with all our focus on Dad's day-to-day needs, we forgot that bills keep coming and the car needs an oil change!

To help, I took over the bills and the health insurance. My brother helped with the car and the household repairs. My sister helped with organizing all Dad's doctor's appointments and medical records. We also couldn't forget about our youngest sister, who was away at college. Dad had a big role to play in her financial aid, and rides back and forth from school.

Looking back now, I wish we had a plan like *Share The Care*. We weren't lacking for family and friends willing to step up and help. We just didn't know where to start. I can't imagine how much less stressful our situation would have been if we had a plan to follow.”

~ Lora Lee La France, Akwesasne

In August, a total of thirty people from the community of Akwesasne and surrounding areas were certified in the “Seeding Share The Care™ in Your Community” program. Share The Care™ is a grass-roots caregiver model/book entitled: *Share The Care, How To Organize A Group To Care for Someone Who Is Seriously Ill*. It is the guidebook for family and friends to organize and maintain their own “caregiving family” for support. The model's systems and forms were created to prevent the primary caregiver from experiencing burnout and/or illness and to support the Care Receiver's ability to stay at home. It puts those offers “what can I do to help” into action. The model has been used for all kinds of challenges from serious to terminal illness; injury to chronic illness; and the difficulties that are associated with aging. It has been used in those situations where grandparents need assistance to care for their grandchildren. And has also been used to help families cope with a difficult pregnancy, premies, and even multiple births. For the last 22 years this grassroots model has successfully helped hundreds of thousands of people across the United States, Canada and other countries cope with the stresses, isolation and depression often associated with caregiving.

The training was a collaboration between the Saint Regis Mohawk Tribe Office for the Aging and ShareTheCaregiving, Inc. and was funded by the New York State Office for the Aging BIP Caregiver Grant. Share The Care™ is the fourth Family Caregiver Education and Training resource of the SRMT-OFA Caregiver Program. The other three resources are: *Powerful Tools for Caregivers*, *Rosalyn Carter Institute's REACH*, and the Center for Loss and Life Transition Grief support group *Understanding Your Grief*.

Our mission is to provide excellent service to seniors by promoting: health, happiness, an active lifestyle, engagement, independence, and long life. Since family members and friends often provide assistance with everyday tasks to help keep their elders safe, healthy, and in their own homes. The Caregiver Program offers specialized counseling and assistance to Family Caregivers including the opportunity for Family Caregivers to take part in many other services. For example, the Health Promotion Services hosts workshops to encourage seniors to remain independent by leading healthier, more active lives and to keep doing the things they love to do. Family Caregivers are always encouraged to attend workshops alongside their loved ones. It is with great pride that the SRMT-OFA Caregiver Program can add another valuable family caregiving resource in the community of Akwesasne.

Culturally, we are known to be a people who take care of our own. Cousins will step in to cook meals for their kin recovering from a major surgery. Co-workers of a mother whose daughter has been hospitalized with a life threatening illness will organize a fundraiser to help with travel expenses. Brothers, sisters, aunts, uncles, grandparents, and even distant cousins will put their lives on hold just to support a loved one in the hospital. And it's not unheard of to overhear hospital nurses and doctors ask "Why are there so many people here?" and are met with this reply "That's a Mohawk patient in that room. Only they have 30 visitors all at once". As a people, we give the time and effort to make others feel comfortable, wanted, and cared for when they are in need. Rare is the situation where a loved one is left to their own devices. There is always someone around to offer help. And as a Mohawk people, we take great pride in being able to lend a hand.

With that, you may be asking yourself: if we're already doing this, then why do we need to use this model? The answer lies in the Lora Lee's story. Unfortunately, Akwesasne has seen and will continue to see families become negatively affected by the onset of a long-term or terminal illness or injury. Often times, Family Caregivers feel they are responsible for every aspect of the caregiving role. They will internalize their feelings if they are overwhelmed with fear. Too often they will tell themselves "I can do this by myself because it is my duty as a wife...husband...son...daughter...best friend...partner...grandchild..." And will only seek help after a crisis happens. When crisis happens, it is because they are not aware of resources available to help them. Or they don't know how to ask for help. Or they are too burnt out and sick and cannot bear yet another task of organizing a team to help. It doesn't have to be this way.

In Lora Lee's case, help was always there. However, her family didn't know "how to begin" to get organized.

Share The Care™ offers a starting point with the all-important first meeting where the family tells the group “This is what’s going on and these are our specific needs.” That way all members of a “Share The Care Group” can understand the situation and individuals can chose the jobs they feel most confident doing. There is even a special form used at the meeting to help uncover the skills, talents and resources within the group. The purpose of the meeting is for people to connect, bond, learn about the model and leave with a sense of purpose. The family benefits from feeling the love and concern from those in attendance.

Share The Care™ is structured so that families don’t have to keep asking for help. Each week, two team members call them to learn what is needed and get the jobs filled. The group will work to keep things up-to-date and organized and share the workloads so that no one person has too much to do. A Group supports, not only the person needing the care, but also their entire family unit. When someone is ill, the whole family is hurting.

We will be offering workshops to help families implement Share The Care™ for their situations. All that’s needed to begin are two people who are willing to be the “Organizers” of the group’s first meeting and to work with the family to figure out who to invite and what kind of help is needed. This is **not** a task for the Family Caregiver. Chapters 1-9 of *Share The Care* are written for the Organizers providing them with step-by-step instructions and a script for the first meeting.

The workshops will show that Family Caregivers don’t have to carry all the responsibility of care. The Family Caregiver and two Organizers will be walked through the all the steps of starting their own, unique group that same day. They will learn tips and strategies on how to keep the group going when times are difficult. They will receive all the materials, resources and encouragement they need to implement the model themselves.

Anyone in Akwesasne can learn about the model by contacting the **Share The Care™ Station** at (518) 358-2963 ext. 3303.