



Regional Caregiver Networks in Newfoundland and Labrador

created by the
Caregivers Out of Isolation Program,
Seniors Resource Centre of Newfoundland & Labrador
2006



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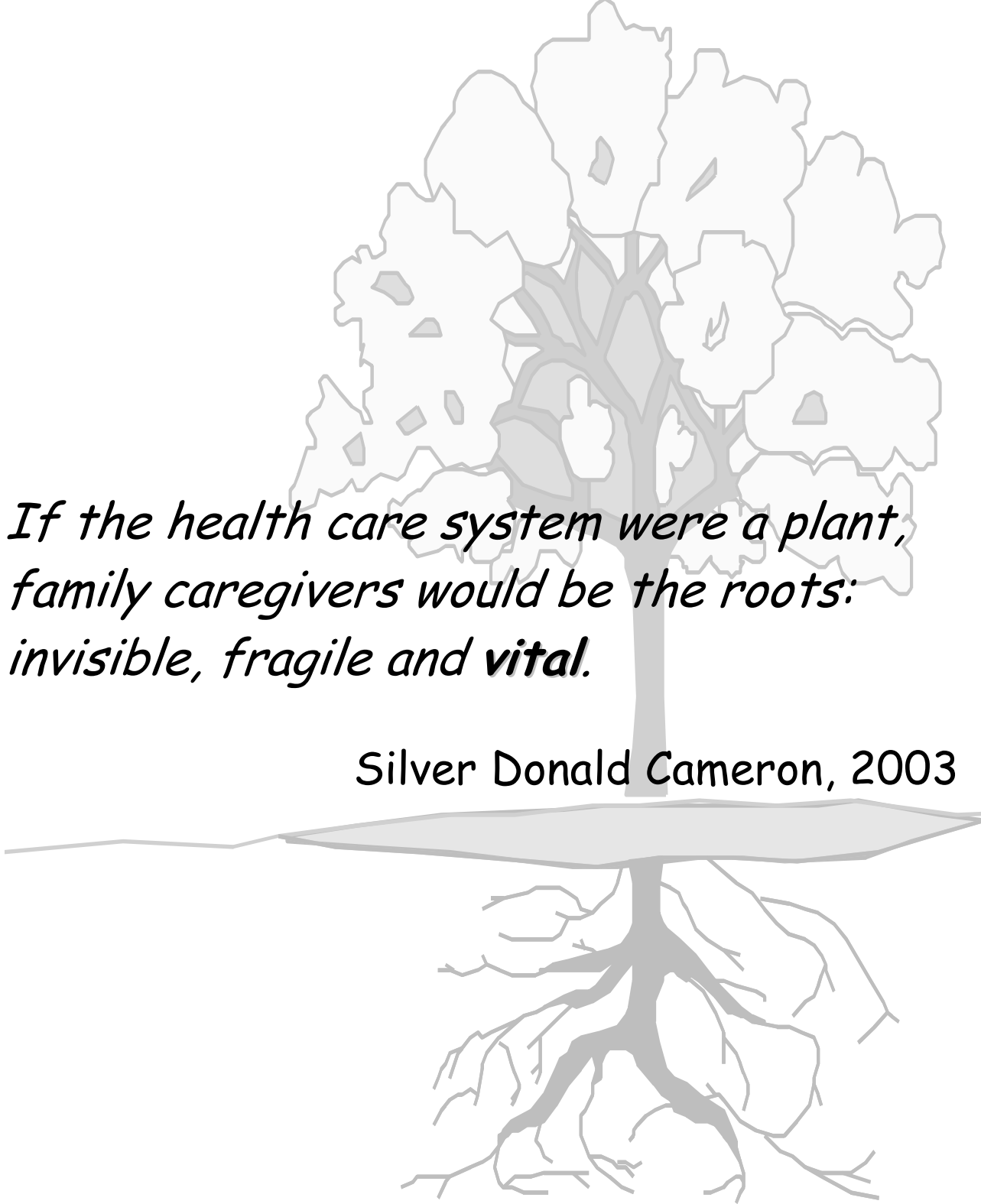
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Please note: We encourage you to use and adapt the information contained in this guide. When doing so, we ask that you acknowledge the source of ideas as the Newfoundland and Labrador Caregivers Out of Isolation program and/or the Newfoundland and Labrador Regional Caregiver Networks. If you have any questions, call the Caregiver Line (709-726-2370) or the Seniors Resource Centre of Newfoundland and Labrador (709-737-2333).



*If the health care system were a plant,
family caregivers would be the roots:
invisible, fragile and **vital**.*

Silver Donald Cameron, 2003

Acknowledgements

We are very grateful to the J.W. McConnell Family Foundation, who have always stood behind what we do. Their funding has made the development of the Regional Caregiver Networks and, more recently, the creation of this guide possible. We are pleased that the Government of Newfoundland and Labrador, Department of Health & Community Services recognizes the value of Caregivers Out of Isolation, providing resources for us to continue beyond the 5-year McConnell-funded project. Thank you to the VON, our project intermediaries, and to our project partners across the country. Sharing our experiences through the Care Renewal initiative has been both thought-provoking and inspiring.

A very big, heartfelt thank you to all the members of Regional Caregiver Networks across the province and to our provincial advisory committee who have contributed countless ideas and provided feedback on the multiple drafts that were sent their way. Far beyond the guide, the passion and commitment of these people to supporting family caregivers has built the Newfoundland and Labrador Regional Caregiver Networks.

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More than anyone, we would like to recognize all of the family caregivers in Newfoundland and Labrador, who do so much with great love. Thank you for your patience and guidance, and for your generosity in supporting other caregivers through the Regional Caregiver Networks. You are incredible people.

...Erin Holland

TABLE OF CONTENTS

Introduction.....	1
Key Terms.....	3
Background: the N.L. Regional Caregiver Networks.....	4
Communities Reached by the Provincial Program.....	5
Guiding Principles.....	8
Why People Have Joined Regional Caregiver Networks.....	9
"Incredible Devotion" - A Caregiving Relationship.....	10
The Regional Caregiver Network Model.....	13
Network Membership.....	13
Caregivers as Network Members.....	15
Community Partnerships.....	17
Linking Regional Caregiver Networks Provincially.....	19
Goals & Objectives.....	21
Getting Started	23
Prepare for a Planning Meeting	23
Identify Key Community Contacts.....	23
Promote the Meeting.....	23
Remind Everyone about the Meeting.....	24
Hold a Planning Meeting	24
Regional Caregiver Network Roles:	27
Meet Regularly	29
Organize Activities for Caregivers.....	31
Attracting Caregivers.....	31
Inviting Caregivers.....	32

Hosting an Activity.....	33
Small and Often	35
Specific Activities	36
Caregiver Day Away	36
Information Session	37
Tea & Talk.....	38
Caregiver Potluck.....	38
Caregivers Panel.....	38
Raise Community Awareness.....	41
The Media.....	41
Presentations.....	42
Displays.....	42
Brochures.....	43
Be Creative.....	43
Increase Local Supports for Caregivers.....	45
Caregiver Phone Buddies.....	45
Friendly Visiting	45
On-Call Volunteers	46
Caregiver Support Groups.....	47
Caregiver Social Groups.....	47
Reach Out to Smaller Communities.....	49
Provide One-on-One Support to Caregivers.....	51
Promote Policy Change.....	53
Addressing Individual Problems.....	53
Addressing Community Issues.....	53
Reviewing Policies.....	54
Presenting Recommendations.....	55
Working Together with Provincial & National Organizations.....	55

Provincial Caregivers Week.....	57
Organize an Event for Caregivers.....	57
Involve Local Businesses.....	57
Contact the Media.....	58
Involve Well- Known Local People	58
Caregiver Appreciation Cards.....	58
 Lessons Learned.....	 59
Sharing Responsibility.....	59
Avoid Volunteer Burn Out	59
Leadership.....	60
Maintaining Momentum.....	60
 Conclusion.....	 61
 Appendices.....	 63
Appendix A Tips	63
Appendix B Setting Goals & Objectives.....	71
Appendix C Media Kit.....	75
Appendix D Fact Sheet	81
Appendix E Caregiver Icebreaker.....	85
Appendix F Planning a Caregiver Day Away.....	89
Appendix G NL Caregiver Week Proclamation.....	93
Appendix H Caregiver Appreciation Cards.....	97

Introduction

Family caregivers play an essential role in Canada, providing unpaid care and support to their family members and friends. Caregivers are involved in providing assistance to one or more people dealing with physical and developmental disabilities, mental illness, aging-related issues, chronic illnesses, and degenerative diseases. Family caregivers provide unpaid support at home, in facilities and in hospitals. In 1999, Guberman estimated that at least 80% of care is provided, **not** by nurses, doctors and the other health professionals, but by family caregivers. A Newfoundland and Labrador provincial government survey in 2001 estimated that 14% of adults aged 18 to 64 cared for others without pay on a regular basis. A 2004 survey of family caregivers connected to the Newfoundland and Labrador *Caregivers Out of Isolation* project revealed that 66% of those interviewed were providing 24-hour care and 59% had been providing support for over 5 years.

The human side of these statistics is complex: for most, caregiving is not a job or a set of tasks, but a relationship that involves love, commitment, exhaustion, frustration, joy and fulfillment. Nevertheless, when supports for caregivers and care receivers are inadequate, caregivers are at risk for burnout. In Newfoundland and Labrador, as elsewhere, changing social factors have led to increased responsibility for family caregivers. Out-migration and women entering the paid workforce, for example, have both led to fewer people with less time taking on increased caregiving responsibilities. More than ever, there is an urgent need to ensure these often-invisible heroes receive some of the recognition and support that they deserve.

In the year 2000, the first caregiver network was formed in Newfoundland and Labrador. A group of people in this province who felt passionate about supporting caregivers of family and friends decided to meet regularly to focus on caregiving issues. Since that time, a number of Regional Caregiver Networks have developed province-wide. The Networks are linked through a community-based provincial program at the Seniors Resource Centre of Newfoundland and Labrador called "*Caregivers Out of Isolation*." The Networks vary from region to region, as they are based in communities of varying sizes and in regions with different geographies

and social factors. Nevertheless, the Networks also have a lot in common, including membership made up of caregivers, representatives of organizations, and other interested people in the community; hosting activities for caregivers and raising community awareness about caregiving-related issues.

The Regional Caregiver Network model is particularly useful in rural communities. Family caregivers who live quite a distance from a larger community¹ would have far different access than those in major cities to programs, such as recreation, and to community-based organizations that provide information and resources. Access to services is further reduced in the winter when treacherous conditions often limit travel. A caregiver living in a rural community in Newfoundland and Labrador may find support through the toll-free Caregiver Line and a sense of connection through the Caring Solutions newsletter. For many, however, a far better option is for them to connect with other caregivers and professionals through locally based Networks. Not only do the Networks host local events, they can also have an ongoing presence in the community, influencing how the community responds to the needs of local family caregivers.

The following guide is a summary of what we have collectively learned so far about building and maintaining Regional Caregiver Networks. Our work is an ongoing process; as our work continues, our ideas will continue to evolve. We encourage you to choose which parts of this guide are relevant to your work. We don't expect you to carry out everything described in the pages that follow; it would, for example, be almost impossible to tackle all of the activities on page 27: *Regional Caregiver Network Roles*. Instead, we hope that some of our experiences and ideas will assist you in reaching out to caregivers, especially those in rural communities.

¹ (In Newfoundland and Labrador, a major "hub community" may have a population of as little as 5 000 – 20 000 people)

Key Terms

Caregiver (Family Caregiver, Family/Friend Caregiver) - someone who provides unpaid care and support to a family member, spouse or friend with an illness or disability. Please note: this term is also used to describe paid home support workers. For the purpose of this Guide, the term caregiver refers solely to those providing unpaid care.

Person Receiving Care (Care Receiver) - someone with an illness or disability. It should be emphasized that this role is not passive; the person receiving care often negotiates the terms of their care with the many players, both professional and friends, who can be involved. Further, the caregiving relationship is reciprocal, with the care receiver giving the caregiver their trust, while the caregiver receives life satisfaction and, often, the care receiver's friendship and love.

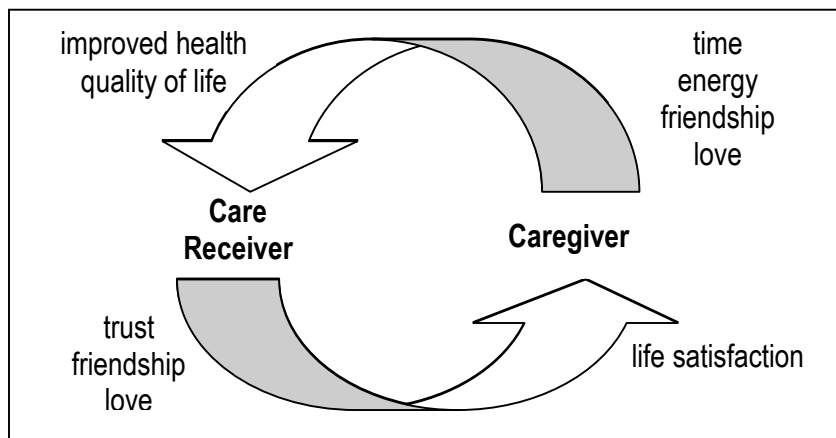


Figure 1: the Caregiving Relationship is Reciprocal

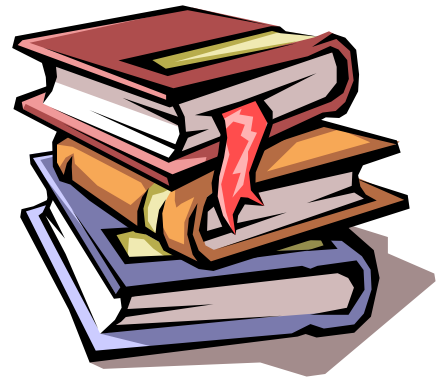
Regional Caregiver Network: A regionally²-based forum of community groups and agencies, as well as caregivers themselves, who identify common concerns, share information, identify ways to support local caregivers and advocate on major policy issues affecting caregivers. In Newfoundland and Labrador, some of these groups have chosen to call themselves, "Caregiver Support Committees." In this guide, we will use the term "Regional Caregiver Network" in order to keep it simple; however you should be aware that not all groups use this term to describe themselves.

² In this case, the term "region" does not refer to any official provincially designated regions, such as those associated with Newfoundland and Labrador's Health Boards or the Rural Secretariat. Some Regional Caregiver Networks have attempted to reach those in a wider area; while others focus more on the community they're based in.

Background: the Newfoundland and Labrador Regional Caregiver Networks

In 1999, a year before the *Caregivers Out of Isolation* project was launched, a number of representatives from Newfoundland and Labrador organizations came together at a caregiving conference at Mount St. Vincent University, Nova Scotia. At the end of the conference, they set themselves the modest but achievable goal of continuing to meet on a regular basis to discuss the activities of each of their organizations as they related to family caregiving.

In 2000 the *Caregivers Out of Isolation* project was established by the Seniors Resource Centre of Newfoundland and Labrador, with a grant from the J.W. McConnell Family Foundation. At that time, the Foundation had launched a 3-year national initiative to support innovative approaches to obtaining "Respite for Family Caregivers." Initially, the Seniors Resource Centre's project's goals were to *identify* the needs of family caregivers, *connect* them to information and other resources, and *stimulate* support for caregivers through community volunteer groups and formal caregiver systems. After establishing a toll-free Caregiver Line, a newsletter and assessing caregivers' needs province-wide, it soon became apparent that there were minimal resources available for family caregivers in Newfoundland and Labrador, especially in rural communities. Expanding on the networking model established by the organizations involved in the Mount St. Vincent-based initiative described above, the project started to facilitate the development of Regional Caregiver Networks, based in various communities throughout the province.



It is significant to note that these Networks were not a goal of the original project, but grew out of a need. At the end of Phase 1, the project was granted an additional 2 years to further explore the concept of Regional Caregiver Networks, especially in relation to rural communities. The Networks and provincial coordination through the *Caregivers Out of Isolation* program now continue with a grant from the Government of Newfoundland and Labrador.

Communities Reached by the Provincial Program

Currently, the *Caregivers Out of Isolation* program reaches caregivers in almost 150 communities, and supports Regional Caregiver Networks in the following areas (note: for more information, please refer to the maps on the next 2 pages):

- Avalon East (based in Mt. Pearl/ St. John's)
- Clarenville
- Grand Falls-Windsor
- The Humber Valley (based in Corner Brook)
- Springdale
- St. Anthony
- Stephenville
- Twillingate

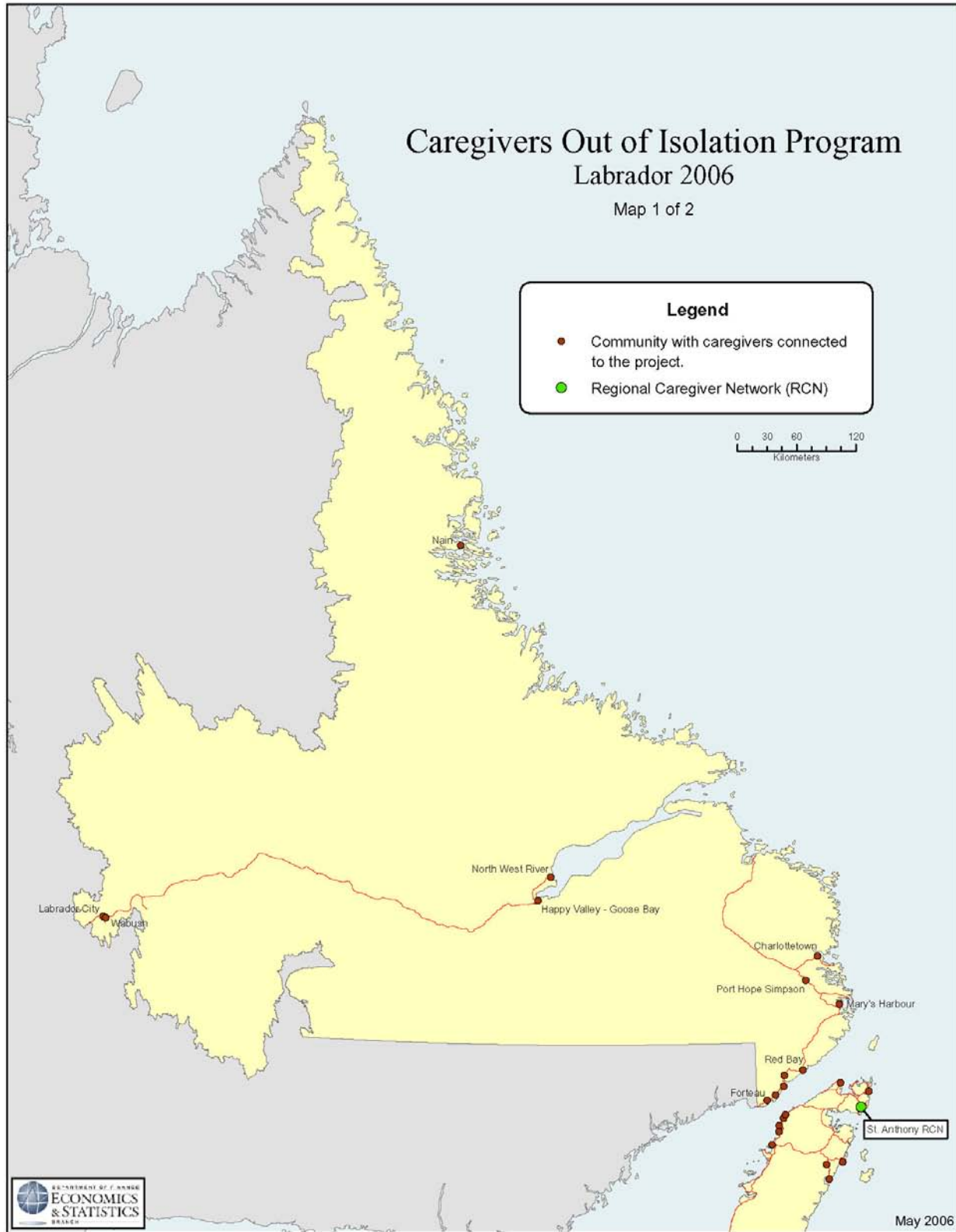
Many communities are not within easy driving distance of the existing Networks and caregivers in these communities have told us that they are unable to attend Network-hosted events. We hope to increase the number of Regional Caregiver Networks in Newfoundland and Labrador, so that the impact of this initiative will continue to grow. If you are interested in potentially starting a Regional Caregiver Network in your community, please call the *Caregivers Out of Isolation* program coordinator at:

The Newfoundland and Labrador Caregiver Line

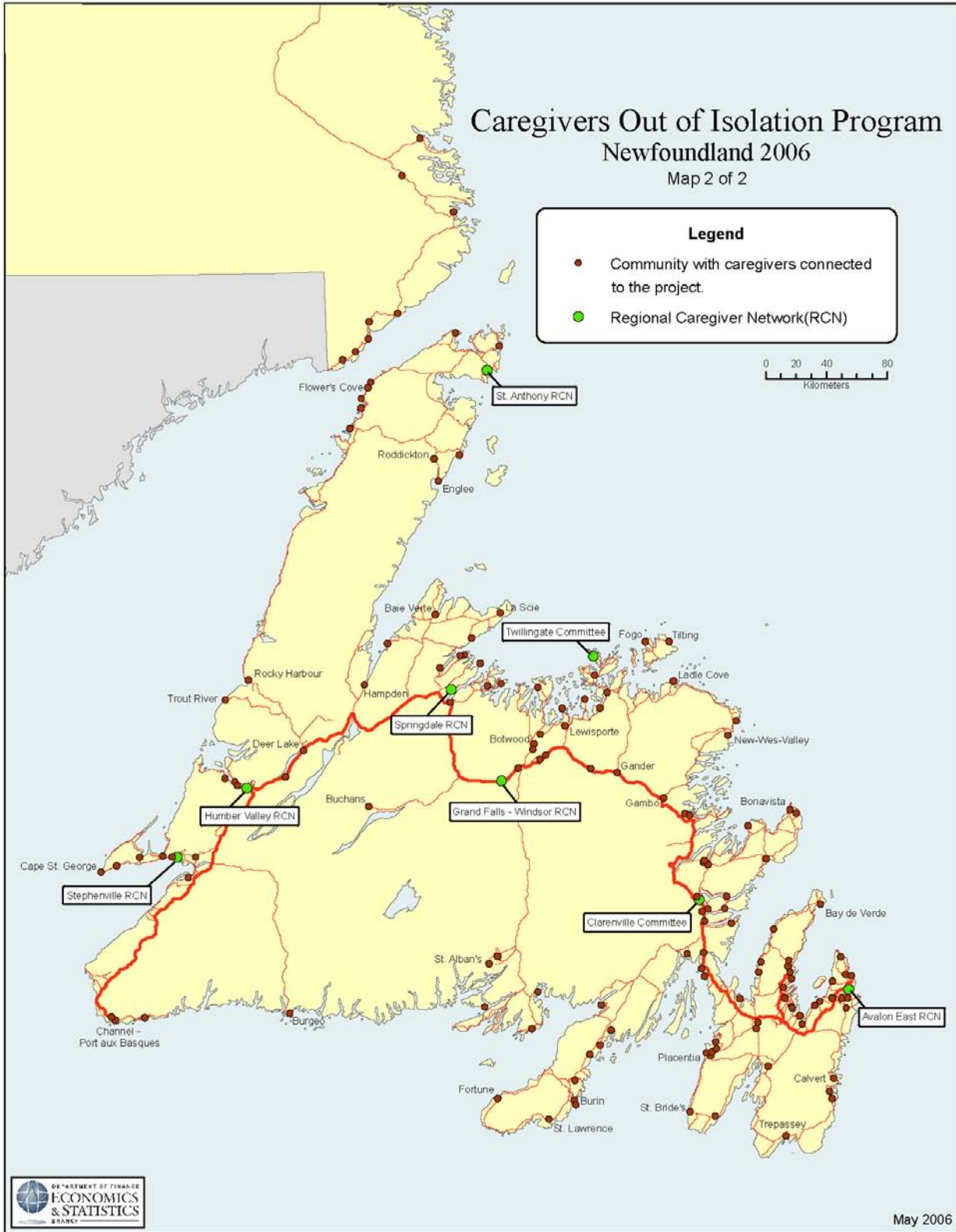
1-888-571-2273 or
709-726-2370



How We Grew: Regional Caregiver Networks in NL
Caregivers Out of Isolation, 2006

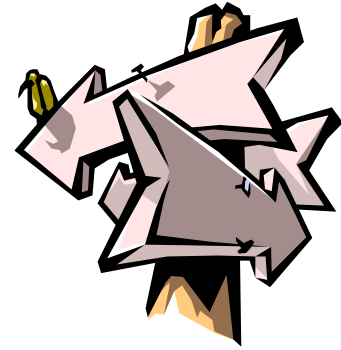


How We Grew: Regional Caregiver Networks in NL
 Caregivers Out of Isolation, 2006



Guiding Principles

The organizations participating in the J.W. McConnell Family Foundation's Care Renewal initiative are very different in scope and approach. They include: the Alberta Caregivers' Association, the Canadian Association for Community Living, Caregivers Nova Scotia, CLSC Rene Cassin, Hamilton CaReS, Lighthouse/Le Phare, MS Society of Canada, Pauktuutit Inuit Women's Association, Schizophrenia Society of Canada, Toronto's Providence Centre, Victoria's Family Caregiver Network Society, VON Canada and, our own, **Seniors Resource Centre's *Caregivers Out of Isolation*** initiative.



Despite their differences, in Phase I of the national initiative, participating projects agreed upon the following principles to guide them in their work. The following excerpts are taken from the February 2005 Care Renewal publication, *Building Respite Knowledge, Issue #1*:

Caregiver Voice - Are caregivers able to define what respite [*see definition below*] means and feels to them? Are caregivers involved in developing, implementing and evaluating programs and policies that affect them?

Caregiver Choice - Do caregivers have access to options that meet their identified needs? Do caregivers have a choice to be or not to be a caregiver?

Respite as Outcome - Refers to a caregiver's emotional, psychological, spiritual, physical and/or social relief or renewal which results from services, activities and strategies intended to help them maintain their own health and achieve greater balance in their lives.

Please note: The term "respite" typically refers to a particular service provided by the health care system where the caregiver gets a break for a week or two through a government-subsidized program. The concept of "respite as outcome" emphasizes that all caregivers experience a break and a feeling of relief in different ways, not necessarily from a specific kind of service. The key to

ensuring caregivers experience "respite as outcome" is to try to support respite as defined by each individual caregiver.

As the McConnell Foundation's national initiative grew into Phase II, called "Care Renewal," participating projects have agreed to add the following principles:

Caregiver Empowerment - How are caregivers included in decisions that affect them in their caregiving relationship? How do we engage caregivers in a partnership without exploiting their willingness to give care?

Sustainability - How do we sustain the concept of "respite as outcome"? How do we integrate our learnings to sustain the work of the projects beyond the Foundation's funding?

Knowledge Transfer and Exchange - How can the knowledge gained from the [Care Renewal] projects be effectively shared and utilized by others (i.e. individuals, organizations, etc.)?

Why People Have Joined Regional Caregiver Networks

- Interest in caregiving issues
- Representing an agency with a mandate to support caregivers
- Personal experiences with caregiving - those who say they've *walked this road*
- Enormous respect for the strength and dedication of family caregivers, which many non-caregivers have described as humbling
- Recognition of the unmet needs in our communities
- Compassion
- Passion!

"Incredible Devotion" - A Caregiving Relationship

by Danette Dooley, re-printed with permission from Belle and David

It's just past noon but Belle Bannister is already preparing supper for her husband David. "For the last six months, we have had to feed David his supper in the middle of the afternoon while he's sitting up straight in his chair so that, if he does choke, we can get at him to give him the Heimlich maneuver," Belle says. Belle has been her husband's primary caregiver since David was diagnosed with multiple sclerosis 22 years ago. The once energetic husband and father had yet to reach his 30th birthday.

Multiple sclerosis (MS) is a disabling disease of the central nervous system, the brain and spinal cord. David suffers from a relatively rare type of MS called primary-progressive MS. It's a nearly continuous worsening of the disease from the beginning with no clear relapses or remissions. "You can have the remitting type where you're pretty good and then you can have another attack," Belle says from her home in St. John's. "But David never had it like that. He had a lot of symptoms by the time he was diagnosed and it's been constant from the beginning."

Belle's caregiving time with David is 24 hours a day, seven days a week. Many tasks associated with her husband's daily care require two people. She gets help from three home support workers, who mean a great deal to her family. It would be impossible to do it alone, she says. "After his breakfast in the mornings, we get David into the bath. By the time we get his equipment on him and get him into the bath and out again and positioned in the bed - that takes about three hours." Like many caregivers, Belle is also her husband's prescription dispenser. He takes about 20 medications that have to be given at specific times throughout the day and night. His special diet also takes much preparation. Her husband's schedule also includes physiotherapy sessions and occasional trips to the hospital. When he's settled for the evening, Belle has a little time to herself. However, her focus always remains on her husband and his every need. "I can't get on the phone because he chokes on his saliva. And I can only put the bed up a little amount because he's not comfortable, there's too much pressure if it's up too high. So I

can't really be on the phone or I can't listen to music in case he might choke and I wouldn't hear him."

While caring for her husband 24 hours a day is no easy task, Belle does so quietly and without complaints. Those traits seem to be a common thread among family and friends who devote their lives caring for their loved ones. Their glass is always half full rather than half empty. "It's really not so bad," she smiles. "We watch TV together, especially in the evenings, and this has become the norm. It's what we live for and, if he's comfortable, we can enjoy that."

David was a construction estimator before multiple sclerosis, Belle says. "We were both working and our son was young, in elementary school, when David got sick. We hadn't gotten to the point where we could take vacations because we were putting all our efforts into getting a house. We were in the process of selling our first house and moving here when David got sick. He wasn't really sick at the time, but his balance was bad. He fell down the steps the first day when we were moving. And he drove off the road once and fell off a building. He just didn't know what was wrong with him," Belle says of her husband's condition before he was finally diagnosed with MS.

Because of the type of MS he has, David has gotten progressively worse. It's a total body disease. Being diagnosed with it in the prime of his life was devastating for them both. Belle is grateful to the MS Society, which provides some funding for the equipment her husband needs to live at home. David doesn't like hospitals, she says. But with help from his home support workers things have worked out well. She worries though that the workers will leave for better paying jobs. "Because the wages are so low, these workers are forced to work two jobs. My worker who is here today now will get off here and then go work another job this evening. And my other worker who was here and was really good, he was stolen away by the Health Care Corporation because they pay double the wages."

For David, living with MS is like being trapped within his own body. While he has some memory loss and cognitive problems, he's very much aware of everything going on. After the interview, Belle goes into her husband's room. She asks David, who is lying in bed watching a movie with his home support worker, if he would mind having his picture taken for the caregiver story that she'd mentioned earlier in the day. He agrees.

A handsome, well-built man, David is over six feet tall and about 185 pounds. After introductions, he asks a few questions about the article and what information will be included. When told it's a story that will give some publicity to caregivers like his wife, he smiles and confirms once more, that it's OK to take his picture for the story. "Yes, she looks after me good," he says slowly but assuredly. "But you wouldn't want to be around when she tries to get me to eat broccoli," he jokes. "Now, that's enough out of you," Belle says fondly, moving toward the bed to sit next to her husband for a photo. While his body weakens, the love between husband and wife strengthens. They've now been married 32 years. She has known David longer with MS than without it.

Though it's difficult at times, caregivers need to look after themselves in order to help others. Belle suggests those caring for a loved one seek home support services earlier rather than later. By the time the services are needed, the caregiver may be too emotionally drained to go through the process. "It's like you're living for two, but you've only got the energy for one. So you're stretched. But the reward at the end of the day is just the fact that you've gotten through your day. And David is as healthy as he can be. He's well fed and well taken care of. And that's what you focus on. And if it was me who'd gotten MS instead of David, I'm thinking he'd be here for me, too," she smiles.



The Regional Caregiver Network Model

Regional Caregiver Network: A regionally³-based forum of family caregivers, community groups, agencies and other community members who identify common concerns, share information, identify ways to support local caregivers and advocate on major policy issues affecting caregivers⁴.

Network Membership

The key to building a good Network team is having broad representation from across the community. Your team should reflect the diversity of situations related to caregiving: physical and developmental disabilities, mental illness, aging-related issues, chronic illnesses, and degenerative diseases. It is invaluable and very important to include caregivers and former caregivers involved in the above kinds of situations (for more information, see the following section, *Caregivers as Network Members*).

Involving a variety of local organizations and agencies is positive in many ways:

1. In addition to their time and ideas, representatives of these groups each bring the experiences of their groups' members. A representative from the Parkinson's Society, for example, would try to make sure that the Network is beneficial for caregivers dealing with Parkinson's disease.
2. Many organizations can also contribute some resources to your Network's efforts, including materials such as paper and prizes, services such as photocopying and phone, as well as expertise such as writing or media

³ In this case, the term "region" does not refer to any official provincially designated regions, such as those associated with Newfoundland and Labrador's Health Boards or the Rural Secretariat. Some Regional Caregiver Networks have attempted to reach those in a wider area; while others focus more on the community they're based in.

⁴ As previously noted, in Newfoundland and Labrador, some of these groups have chosen to call themselves, "Caregiver Support Committees." In this guide, we will use the term "Regional Caregiver Network" in order to simplify things; however you should be aware that not all groups use this term to describe themselves.

skills. If each organization helps out in small ways, the combined effort is often impressive.

3. Organizations have numerous contacts. They can share information, invitations, etc. with caregivers and other community contacts.
4. Organizations can also bring information to the Network, telling other Network members about events and/or resources that might benefit caregivers and their families.
5. Participation in a Network can also lead to changes in the organization itself. Through their involvement, some organizations start to put more of an emphasis on supporting caregivers.

The following groups are represented in our Networks:

- ⇒ Caregivers & former caregivers (for more information, see page 15)
- ⇒ Regional branches of national not-for-profit organizations such as the VON, the Canadian Cancer Society and the Women's Institutes
- ⇒ Regional representatives of provincial organizations such as the Newfoundland & Labrador Association for Community Living and the Seniors Resource Centre of Newfoundland and Labrador
- ⇒ Regional reps of provincial government such as the Rural Secretariat
- ⇒ Local not-for-profit organizations such as the Mount Pearl Seniors Independence Group
- ⇒ Health professionals from the Regional Integrated Health Authorities (former Health & Community Services), including public health nurses, social workers, occupational therapists, nutritionists, etc.
- ⇒ Members of the Primary Health Care Community Advisory Committee⁵
- ⇒ Local churches and other faith communities
- ⇒ Interested community members

⁵ The Twillingate Caregivers Support Committee was started through their Primary Health Care initiative – the link with our program and the other Networks has been positive for everybody.

Caregivers as Network Members

Regional Caregiver Networks were originally formed with representatives from organizations and agencies. Because caregivers are already stretched in many ways, we avoided asking them to commit to "behind the scenes" planning and meetings. Instead, Networks planned activities based on caregivers' suggestions.

Over time, it has become increasingly clear that having caregivers as active Network members is positive for many reasons, including those described below:

Why to make sure caregivers are a part of your committee:

- (1) Caregivers are the true experts when it comes to caregiving and should be involved in all decisions that your committee makes;**
- (2) Caregivers' presence at meetings helps sustain other members' passion for supporting caregivers;**
- (3) The relationships which caregivers develop with other committee members validate the importance of their expertise and experience;**
- (4) Former caregivers, who often describe feeling at a loss when the person they are caring for has died, can use their experience to help other caregivers;**
- (5) Most importantly, the caregivers who choose to become involved are energized and often experience a break from caregiving as a result of their participation.**

Now, newer groups in Clarendville and Stephenville consist almost entirely of caregivers, with professionals involved as resource people. These groups both attribute their success to keeping their meetings informal and fun. Phone reminders from other caregivers seem to add a personal touch that encourages caregivers to attend meetings.

When recruiting caregivers to join your Network, involve them in setting objectives and ask whether they are able to help pursue these objectives.

Caregivers will become more enthused about helping to achieve specific goals than if you just invite them to join your committee.

At meetings, use clear concise language which can be easily understood. Professionals have a tendency to use jargon that caregivers may not understand. Avoiding these words is a way to make sure everyone can follow the conversation and, in doing so, feel like a part of the team.

TIP #1

Enabling Caregivers to Join Network Planning

- Schedule meetings based on the availability of interested caregivers (e.g. afternoons)
- Try to supplement costs of replacement care (also known as "respite")⁶
- If needed, help with transportation needs/costs
- Ensure that discussions are in plain language, so that everyone feels included

Notes:

⁶ When you advertise that you may help caregivers to cover replacement care, you may be surprised how few caregivers actually make a claim. Some groups expressed concern that the number of requests would be outside their budget. The Western Coalition to End Violence organized 2 events in Stephenville, announcing on all their invitations that "replacement cost for caregivers is available (limited amount)". There was a large attendance for both days, and only 2 claims were made. Nevertheless, some caregivers commented that the organizer's recognition that some caregivers might need this help made them feel more welcome, even if they didn't need to request financial assistance.

Community Partnerships

Strong links with local partners are important, whether they are members of the Network who meet regularly, or community contacts who understand and support what the Network does. The following are suggestions of potential local partners and roles they might play in supporting your efforts:

Local Businesses, (e.g. restaurants, gas stations, homecare agencies, etc.) may donate prizes & food, put up posters and displays.

The Regional Integrated Health Boards may support your Network through in-kind services such as mail-outs, or review caregivers' suggestions for policy/program changes. These boards include public health nurses, etc. who are also very supportive (see ⇨).

Public Health Nurses, Occupational Therapists, Social Workers, etc can identify key community members to include in the Network, help direct you to community spaces in which to hold events, distribute Network invitations to their caregiver "clients" and provide in-kind services.

Individual Volunteers can be asked to help out with specific tasks, such as meal preparation, entertainment and driving.



Media may feature caregiving-related stories including interviews with local caregivers, create a regular "Caregiver's Corner/Column," announce upcoming events for caregivers in community calendar, promote the Network.

Service Clubs may provide community halls for meetings, donate prizes and food, make food, etc.

Churches/Faith Communities may announce upcoming events in church bulletins, make announcements about supporting caregivers, donate food and door prizes, or provide volunteers.

Not-for-Profit Organizations may promote your Network to their clients, provide space & volunteers, do presentations at information sessions, put up displays in their office, etc.

Community Grants are another potential boost for a Network. Having some money to put towards activities, including: paying for transportation and/or homecare to enable more caregivers to attend, inviting speakers, and purchasing resources such as videos or books.

Local Colleges/Universities:

Students can be an excellent asset to your Network. Potential student roles include organizing smaller social events; developing displays, presentations, brochures, etc; seeking donations; supporting new activities such as a volunteer network and, with adequate supervision and training, phoning caregivers for emotional support.

Work Experience Programs:

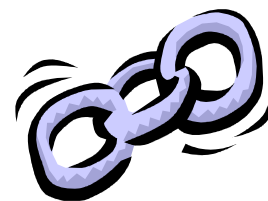
Your Network could benefit from various job creation programs. Check with your local Human Resources Labour & Employment office and keep an eye out for programs that hire people who need job experience. Most of the suggestions related to students on this page would also apply to hosting interns through work experience programs.

TIP # 2

If you choose to have a student, we suggest...

- Set clear achievable goals, re-evaluating regularly.
- Set up a clear system for supervision. The Avalon East Network has set up a supervisory team.
- Share responsibility - In the Humber Valley Network, one person prepared the proposal, another agreed to host a student at their organization, and two more agreed to supervise and deal with administrative tasks.
- As part of the orientation process, ask caregivers in your area to talk to the student about what it's like to be a caregiver. You may need to emphasize that this is not for "counseling," but for caregivers to share their expertise and experience.

Linking Regional Caregiver Networks Provincially



It is invaluable for Networks across the province to be able to link, sharing ideas and resources. The St. Anthony Network, for example, created a booklet called "Caring for the Caregiver" which other Networks have used in their regions. Collectively, the Networks can be stronger in providing a voice in policy issues, or in launching province-wide awareness campaigns. A very successful example in Newfoundland and Labrador is provincial Caregivers Week, where Networks host activities and collaborate to promote information about caregiving in the local media (see page 57).

Network members have strongly emphasized that they need a provincial coordinator in order to link and to sustain the Regional Caregiver Networks. Experience has shown that the coordinator can provide invaluable support information and linkages.

WHAT WE'VE TRIED	WHAT WORKED	WHAT DIDN'T WORK	Recommended?
Hold provincial meetings attended by representatives of each Network	<ul style="list-style-type: none"> • Network members enjoy connecting face-to-face • Feeling of "team spirit" increases 	<ul style="list-style-type: none"> • More expensive than other means 	YES
The provincial advisory committee, which meets by teleconference, includes one rep. from every Network	<ul style="list-style-type: none"> • Same benefits as provincial meetings, above • Network members are directly making decisions about provincial staff's activities • Network representatives provide brief regional updates verbally 	<ul style="list-style-type: none"> • Teleconferences can be hard to follow, especially for new people • Network representatives must communicate well with their Networks, speaking on their behalf and sharing information about decisions made 	YES
Each Network shares a summary of what they're doing with the other Networks	<ul style="list-style-type: none"> • Can see what's happening in other regions of the province • Networks can get ideas from each other 	<ul style="list-style-type: none"> • Too time-consuming to write summary • Too time-consuming to read summaries from all Networks 	NO
Each Network shares minutes from their meetings with all the others	<ul style="list-style-type: none"> • Can see what's happening in other regions of the province • Networks can get ideas from each other 	<ul style="list-style-type: none"> • Too time-consuming to read summaries from all Networks • Minutes don't always make sense if you aren't a member of that Network 	NO

Other helpful “tools” for linking provincially:

☆ **Provincial Newsletter**

In Newfoundland and Labrador, the *Caregivers Out of Isolation* program publishes a quarterly newsletter for family caregivers and those who work with caregivers. The “Caring Solutions” newsletter shares information with caregivers and recognizes their important role. It has also become an excellent tool to link Networks provincially by providing updates on Network activities and upcoming events. Because the Networks are all fairly unique in what they do, it is helpful for a sense of “provincial identity” to see all of the Networks described in one publication.

☆ **Provincial Website**

A shared website (www.caregiversNL.ca)⁷ has also been an asset to linking caregivers and Networks throughout the province. With someone to update it regularly, we believe that it has great potential to reach more caregivers and, especially, to reach professionals who could share the information with their clients.

☆ **Provincial Caregiver Line**

Our toll-free Newfoundland and Labrador Caregiver Line (1-888-571-2273) connects caregivers from across the province with the Regional Caregiver Network closest to their communities. The Caregiver Line also helps the provincial program to identify communities that have interest in developing new Networks.

⁷ If you are having difficulties accessing our website, please try following the links at www.seniorsresource.ca

Goals & Objectives

*"If you don't know where you are going, how can you expect to get there?"
Basil S. Walsh.*

Like any group, the Regional Caregiver Networks have found that they work best when they have a clear plan. A plan should include the setting of **goals**, and specific **objectives** for each goal. The following are some examples of Regional Caregiver Networks' goals and objectives:

GOAL #1 - To create more community awareness of caregiver issues

- ⇒ To identify the needs of caregivers in the region
- ⇒ To provide information to caregivers on services and supports in the community
- ⇒ To identify gaps and/or duplication in community services

GOAL #2 - To encourage understanding and co-operation among professional groups, voluntary and government agencies, caregivers and care receivers

- ⇒ To facilitate the exchange of information
- ⇒ To develop and distribute promotional materials for and about the Regional Caregiver Network
- ⇒ To plan and organize an annual caregiver event
- ⇒ To promote the development of community resources and/or programs to support caregivers



* Please note: Your group may want to create even more specific objectives than those above. For example:

- To host 4 information sessions during the year.
- To have 5 articles featured in local newspapers.
- To have at least 50 local caregivers participate in events during the year.

Once you've set your goals and objectives as a group, plan to re-evaluate on a regular basis to find out whether they have been met and/or whether you need to change them slightly. Be sure to celebrate even the smallest steps when they have been achieved.

Remember...



"Every journey begins with a first step. Love your big toe."

Alison Rippin, Victoria B.C.

It will take small steps to make the journey of improving caregiver supports in this province and in this country. Caregiving responsibilities can feel overwhelming at times. The above quote reminds us to appreciate every step, as well as all of the individuals involved in making every step.

For more information about setting goals and objectives, please refer to Appendix A.

**Goals of the Newfoundland & Labrador provincial program,
Caregivers Out of Isolation:**

- 1. To provide direct support to caregivers according to their self-identified needs**
- 2. To enhance awareness about issues identified by caregivers**
- 3. To promote policy development that responds to issues identified by caregivers**



Getting Started...

If you're interested in starting a Network in your community, try to find a couple of people who would be interested in assisting you. The following steps are much easier to accomplish if you start out with a group of at least 3 people:



Prepare for a Planning Meeting

As a small group, make sure you (a) identify clear goals for the meeting (b) write up an agenda and (c) divide the responsibilities for organizing the meeting. Plan to meet at a central, accessible location. Most service clubs have meeting rooms that they offer to groups; community rooms in supermarkets are excellent; local libraries and provincial health offices may also be able to provide space.

Identify Key Community Contacts

Think about who you know in the community, especially caregivers, who might be interested in caregiving issues, or who would know others who are. Contact your public health nurses, clergy, town clerk, family doctors and social workers to get in touch with caregivers and other key people in the community (for ideas of potential community partners, please refer to pages 13-18 of *The Regional Caregiver Network Model*. Use what some call the "snowball method" which, like a snowball, builds momentum by picking up new people as you "roll along." Ask each person you talk to for suggestions of others who might want to be involved.

Promote the Meeting

(a) Through word of mouth - ask all your existing contacts to tell everyone they know; (b) By sending Public Service Announcements to the community events calendars in the local newspapers, on the radio and TV; (c) Through church bulletins; (d) By putting posters and/or flyers in public places such as the post office, grocery stores (on bulletin boards or in grocery bags), gas stations, etc.

Remind Everyone about the Meeting

Everyone, especially caregivers, has a busy schedule. The best way to encourage good turnout is to phone those who have expressed an interest a couple of days before the meeting. For those who are undecided, your phone call will reinforce how much you would like them to come. Reminder phone calls are also an opportunity to try to make transportation and homecare arrangements for those who couldn't otherwise attend.

Hold a Planning Meeting

At the first meeting, you will need to discuss the things you would like to do in the community. As a group, you may try the following ideas:

1. Have each person around the table introduce himself/herself and talk about their personal and/or professional involvement with caregiving. Ask everyone to keep in mind that this should be fairly brief. If they represent an organization, ask them to explain what resources are available to caregivers through their organization (keep notes on a flipchart!).
2. Determine if there are resources in the area in addition to those that have been identified, above.
3. Ask the group to brainstorm the following:
 - The needs of caregivers in your area.
 - What can be done to help address some of those needs.
 - The specific steps (objectives) to help you meet the goals.
Note: these should be practical objectives that are do-able for your community-based group.
 - Who at the meeting can assist in making and what their tasks would be.
 - Who else in the community can help achieve these objectives, what their tasks could be and who will contact these community resource people.

(For more ideas, please see Appendix A: *Setting Goals and Objectives*.)

5. At the end of the meeting, try to leave with a ***clear plan of next steps***. Don't overwhelm people by trying to tackle too much at once, but show them that things are moving forward. As organizers, make sure to divide up responsibilities, making good use of people's skills and contacts.

Note: You may decide as a group to plan a session for caregivers. If so, please refer to pages 31-39, *Organize Activities for Caregivers* for more information.

TIP #3

Make Sure that Caregivers Direct the Network's Objectives

Always try to focus on what caregivers in your region would like you to do. If you need more input, organize a community meeting to ask them.

TIP #4

How to introduce the idea of Regional Caregiver Networks...

During a planning meeting, you should tell participants that other Networks exist. Nevertheless, wait until your group has discussed local issues and possible solutions before talking in detail about other Networks' activities etc.

Regional Caregiver Network Roles

One of the greatest strengths of Regional Caregiver Networks is that they are so different. Each Network needs to decide which roles and activities best meet the needs of the caregivers in their area. **DON'T TRY TO DO EVERYTHING AT ONCE!** The following are some ideas tried by the existing Regional Caregiver Networks (please read the following sections for details about each role):



**How We Grew: Regional Caregiver Networks in NL
Caregivers Out of Isolation, 2006**

Meet Regularly

Regular meetings are held in order to plan activities described in the following sections. These meetings also enable Network members to learn about what is going on in their community to support caregivers. Meetings help maintain members' enthusiasm - because we are involved in many things, the meetings help us to remember why we feel passionate about supporting family caregivers. For the family caregivers who attend, meetings are an opportunity to decrease their feelings of isolation and to see that there are others who care about the "invisible heroes" in our communities.



TIP #5

Set a Regular Meeting Schedule

You'd be surprised how much time and energy can go into setting a date that all Network members can agree on. We highly recommend choosing a day, such as "the first Tuesday of the month from 2 - 4 pm." Keep in mind that weather and other factors may result in the need to re-schedule.

Organize Activities for Caregivers

The following are ideas about organizing activities for caregivers that have been developed by Regional Caregiver Networks in Newfoundland and Labrador. The first few sections are a collection of general tips to keep in mind of activities. These sections include: *Attracting Caregivers*, *Inviting Caregivers*, *Hosting an Activity*, and *Small and Often*. Following these pages is information about organizing specific activities, including: *Caregiver Day Away*, *Information Session*, *Tea & Talk*, *Potluck* and *Caregivers Panel*. We encourage you to use the ideas that fit your community's needs and to combine different parts of the activities described below to create a unique event in your area.

Attracting Caregivers

- ❑ Decide on a **time when many local caregivers are available** (lunchtime and afternoons have worked best in our experience).
- ❑ According to our evaluations, the main feature that initially attracts caregivers is **information**. Make sure to include opportunities for learning in your event, and advertise this in your promotions. For ideas of topics, see page 37, *Information Session*. It is interesting to note that, although caregivers cite information about resources as their motivation for attending activities, it is the social interaction with other caregivers that they rate the most highly at the end of each event.
- ❑ From our experience, providing a complimentary **meal** is another good way to attract caregivers. Because caregivers rarely have opportunities to be served by others, they will especially appreciate this gesture.
- ❑ Make the meeting **short enough** that it will be possible for caregivers to attend, and tell them that if they absolutely can't stay the whole time, they're still welcome to come for part of the session.
- ❑ Some caregivers need **assistance with transportation and/or substitute care** in order to come. Try to find ways for your group to help with this, such as gas vouchers, or raising some funds to help cover costs.

Note: for more ideas about how to attract caregivers, see *Tip #1* on page 16.

Inviting Caregivers

- When inviting caregivers, **give them lots of notice**, as many of them will need to make special arrangements in order to come.
- Ask local workers such as the public health nurses and social workers to **give personal invitations to their clients** who are caregivers. Also ask local/regional/provincial community organizations who have caregivers on their mailing lists (e.g. *Caregivers Out of Isolation* sends a newsletter to hundreds of caregivers from across the province) to send personal invitations to those in your area.
- Ask those interested in attending to **pre-register**.
- **Promote the event in your local media** (see page 41: *the Media* and Appendix B: *Media Kit*). Although it is surprisingly rare that caregivers will call you based on a general announcement, those who have received personal invitations will be more likely to come if they also hear about the event from another source. Don't forget that promoting events through the media always has the double benefit of raising general community awareness as well.
- About 4 days before the event, **it is important to phone** the list of caregivers who have registered to confirm that they are still able to come - it is especially effective to have local caregivers help to make these calls. Many caregivers are reluctant to take time for themselves or to come out to an event which will focus on them. These personal calls are encouraging and help them to feel welcome.
- In addition to inviting caregivers, make sure to **invite other people** in the community who might be able to support any future efforts.

TIP #6

Always Respect Confidentiality

Giving event invitations to organizations helps avoid breaching confidentiality. Instead of asking them to give you their mailing lists, they are able to give invitations directly to their clients who they think might be interested in your event.

Hosting an Activity

AS YOU BEGIN...

- Ask caregivers to sign in** with their name, community and phone number. Announce at the end of the session that you will let them know of any future meetings.
- The organizers of the meeting should **introduce themselves** and explain briefly their **goals for the day**.
- Provide an **icebreaker** to enable caregivers to mingle with each other (see Appendix C: *Icebreaker* for an example). Even in small communities where people usually know each other, your event may be the first opportunity for this combination of people to meet. It's good to use an icebreaker that brings up caregiving, as this is what everyone present has in common. Avoid asking them to share personal information.

DURING THE SESSION...

- Acknowledge and praise caregivers repeatedly for all that they do. We know that you think they're incredible - just make sure to say it.
- Prizes can certainly contribute to a fun atmosphere. Set a modest goal for the number of prizes and don't overdo it! Don't allow the need to collect prizes overwhelm the other goals that you want to achieve.
- Provide opportunities for caregivers to speak and ask questions.

TIP #7

Try holding an event where "care receivers" are also invited.

Sometimes your group may want to open a social event to all caregivers and those they care for. This can be fun for all involved, and provide an opportunity for caregivers to introduce others to some of the most important people in their lives: their family member/friend.

TIP #8

Have fun!

Keep in mind that many family caregivers rarely take time for themselves. Your event might be the first "break" they've had in weeks. Invite local musicians and performers, offer door prizes, have a fun skit (maybe with a caregiving theme), etc. Try to make sure that everyone leaves with a smile on their face.

WRAPPING UP A SESSION...

- Thank everyone for coming - it's not easy for caregivers to make arrangements to come.
- Discuss the session as a group, finding out whether the session met their expectations and ask for suggestions for future events. Provide individual evaluations as well (i.e. by a short written questionnaire filled out at the event or, for those with limited literacy skills, a follow-up phone call). For shy caregivers, this will be a good chance to make sure that you are meeting their needs too.
- Always make sure everyone leaves the meeting with a clear idea of next steps. For example, think about: Will you be holding another session in the next few months that you will send them an invitation for? Would you like to encourage those who are interested to come to the regular Regional Caregiver Network meetings? Are you giving them a list of phone numbers they can contact for support? Can they expect to receive a caregiver newsletter such as Caring Solutions? Even if you don't have an event planned, most will appreciate leaving with a sense of having made an ongoing connection.

TIP #9

Recognize the tremendous role of caregivers again and again and again and again... (you get the idea!) This will be new to many caregivers, who are often impressed by all that others do, but don't recognize their own contribution.

TIP #10

Set realistic goals

If you make plans for the future, keep them DO-ABLE - it's easy to get wrapped up in the enthusiasm and power of the day, and set lofty goals that are impossible to achieve. As organizers, don't make promises that you can't keep.

Small and Often

Regardless of the type of event, caregivers across the province of Newfoundland and Labrador tell us that they simply enjoy the opportunity to meet others who know first hand what it's like to be in their shoes. In our evaluations, caregivers consistently ask Networks to host events more often. The evaluator for *Caregivers Out of Isolation* also suggests, "given the benefits of the Network activities to caregivers... it will be important for regions to continue to host activities for caregivers. This would provide more opportunities, not only for heightened awareness of caregiver issues and of reducing caregivers' isolation, but also to attract a larger population base due to people having more activities [and times] from which to choose" (IHRD, 2005).



TIP #11 **Think Small** **and Often**

Caregivers suggest that, if possible, they would like Networks to hold several smaller activities versus one large-scale activity annually. In our evaluator's words, "*think small and often*"

TIP #12

Share Responsibilities

When you are planning an activity, especially a larger event such as the Day Away, you may want to divide into sub-groups. All members of the Avalon East Regional Caregiver Network work together to organize presenters, displays and volunteers. They also form two sub-committees: (1) donations and (2) media & communications.

Specific Activities:

Caregiver Day Away

This event was started in the year 2000 by Regional Caregiver Networks in Springdale and St. John's. The Day Away is usually a half-day event from approximately 11:00 - 3:00. The Day Away can include icebreakers, presentations (information-based, motivational, etc.), music or skits, volunteer massage and other therapists (*very popular in St. John's*), door prizes, informative displays, a meal that is served to the caregivers (they shouldn't lift a finger!) and, most importantly, opportunities for caregivers to talk to each other. Caregivers appreciate something special that they can take home as a memento of the day. Some popular ideas have been: carnations (Avalon East Network), little trees or plants (Twillingate Caregivers Committee), and bookmarks (Grand Falls-Windsor Network). You might want to attach/include a message such as:



- "While you're caring for others, please don't forget to take care of yourself."
- "If the health care system were a plant, caregivers would be the roots: invisible, fragile and **vital**." Silver Donald Cameron

For more information see Appendix D: *Planning a Caregiver Day Away*.

TIP #13

At a Day Away, focus on fun, relaxing activities

Because the Day Away is an opportunity for some caregivers to "get away from it all" you might want to save more serious topics, like the availability of services, for a separate session. At your Day Away, we recommend circulating a sign-up sheet for those who are interested in attending future information sessions.

Information Session



Most caregivers, especially new caregivers, tell us they want more information to help them navigate the system. (You may want to organize shorter 1-2 hour information sessions on a variety of topics. Here are some themes that caregivers have suggested to us:

- Enduring Power of Attorney/ Advanced Health Care Directives
- How to hire a home support worker
- Relaxation/Meditation/Massage
- Medications (pharmacist)
- Specific diseases - Parkinson's, depression, etc. Note: these are probably already being organized by organizations such as the Parkinson's Society, Canadian Mental Health Association, etc. - check with them first
- Aging issues - as above, we suggest you contact provincial seniors organizations, such as the Seniors Resource Centre or a local group like Mt. Pearl Seniors Independence Group

TIP #14
For ideas of topics... ask local caregivers: at your events, through announcements in the local newspaper, and through the provincial caregiver newsletter, etc.

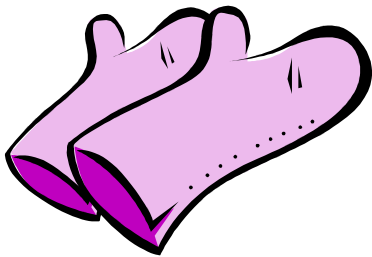
Note: eventually, we hope to collect a series of presentations and/or videos so that, if you can not find a local speaker on a topic, some of your Network members may be able to do the presentation, using these resources. Before developing your own materials, try calling the Caregiver Line at 1-888-571-2273.

Another way to share information is through displays. Ask local organizations and businesses to set up a display at your event and plan time for caregivers to view the displays and ask questions.

TIP # 15
At presentations, allow lots of time for questions. You may want to have prepared a few questions to get the ball rolling, in case participants are shy at first.

Tea & Talk

A "Tea & Talk" is one way to bring together caregivers without having to arrange speakers or a meal. Organizers can focus their time and energy on promotion and invitations. Then, simply provide tea and snacks, briefly talk about the Network and, as always, recognize the caregivers and provide opportunities for them to talk with each other and with Network organizers. The Grand Falls-Windsor Regional Caregiver Network successfully hosted this kind of event in two rural communities, in an attempt to reach new caregivers in their region. They used the help of two students, who assisted with most of the arrangements.



Caregiver Potluck

A couple of years ago, a caregiver in Springdale suggested on their Day Away evaluation form that the Network should host a potluck. Although we questioned whether inviting caregivers to a potluck would only add to their responsibilities (i.e. having to prepare a dish), the Springdale annual Valentine's Caregiver Potluck has turned out to be their most popular event!

Caregivers Panel

Some of us like to call this the "Experts Panel." The most common format is for 3-4 caregivers to sit at the front of the room, often at a table. They take turns briefly telling their stories. Many groups have successfully used the Caregiver Panel to encourage other caregivers to talk about their experiences. After the panel has spoken, open up conversation to anyone else who wants to speak or ask questions. This approach reinforces the message that caregivers are the true experts in caregiving. They know best what it feels like to be a caregiver, the resources you might need, and can provide you with helpful tips. In



Raise Community Awareness

The Media

As described on pages 17-18, *Community Partnerships*, local and provincial media are excellent to approach for:

- ☆ Featuring caregiving-related stories including interviews with local caregivers,
- ☆ Creating a regular feature such as a "caregiver's corner/column" in a newspaper,
- ☆ Announcing upcoming events for caregivers in community calendar, including the "Envision" website and newsletter in Newfoundland and Labrador (www.envision.ca), and
- ☆ Promoting your Network.



TIP #17

When possible, try to approach media people who you know

You can send general media releases, P.S.A.'s (Public Service Announcements) and Fact Sheets to local media outlets (see Appendix B), but for better coverage it sometimes helps to directly approach people you know. Find out who among your Network has media contacts and ask them to follow up.

Coverage by local media reaches two key audiences:

- ⇒ **Caregivers**, who can benefit by knowing about your Network, by learning from information presented in the article, and by being recognized for what they do. Local media coverage will also help you to connect with more isolated caregivers who aren't able to attend your events.
- ⇒ **The general public**, who may be encouraged to increase their support to caregivers they know. People may learn more about the intensity of the caregiving role through your media stories. They may also tell caregivers about your group.

TIP #18

Be sensitive when dealing with caregivers and the media.

The most interesting story is often the caregiver's own personal story. Understandably, caregivers can be reluctant to share this kind of information, sometimes because they don't want the person they're supporting to feel like a burden, or for others to perceive it that way. A caregiver may appreciate the opportunity to review a story before it airs, although this is often not possible due to time constraints. Reassure the caregiver repeatedly that they don't need to talk about anything they feel less than 100% comfortable with.

Presentations

If your Network has prepared presentations about caregiving and about your Network, it is easy to accept and even pursue invitations from local community groups, schools, service clubs, organizations, Regional Health Authorities, etc. The most important part of such a presentation is not the materials you use, it's making sure that your message is clear and that your delivery is heartfelt and "real." If you create a presentation on a computer in PowerPoint, keep in mind that sometimes technology doesn't work as expected. Ask your host whether they are able to provide an overhead projector, and bring overheads as a backup.



Displays

Using the materials from your presentation above, create a simple display that can wait in a drawer or closet for a community event that caregivers are likely to attend. Include individual brochures from the organizations who are members of your Network, as well as handouts from your provincial organization.

Brochures

Brochures about your Network can be left at local clinics and hospitals, community centers, pharmacies, churches, libraries, and at local workshops, conferences and meetings. In the brochure, outline (1) your goals, (2) your region, (3) your connections (if any) to a provincial network and (4) any organizations that are members of the Network. It is important to provide contact information for at least one Network member. If members are reluctant to provide their home phone number, it is helpful to give a contact number for a community group or organization represented in your Network.

Be Creative!

For example, nominating a local caregiver for a prominent award will not only bring well-deserved recognition to the caregiver, but also create awareness about your Network. If they win, send out a media release from your Network to announce the good news. Two Canadian awards are:

★ Grey Power Caregiver Award

www.greypower.com/stouffville/caregiver.html

★ Governor General's Caring Canadian Award

http://www.gg.ca/honours/awards/cca/index_e.asp

You can be very creative with promoting caregivers. One year, the provincial *Caregivers Out of Isolation* program advertised its Caregiver Line at no cost on milk cartons. This was a unique way to reach households across the province, although it did lead to some confusion as a few dissatisfied customers called to complain about leaky milk cartons!



Increase Local Supports

Caregiver Phone Buddies

Based on caregivers' ideas, Regional Caregiver Networks have tried two ways to promote mutual support between caregivers through the phone. Because caregivers often find it difficult to leave the house, we all thought that establishing "phone buddies" would be an easier way for caregivers to feel more connected and supported within their communities.



In Grand Falls-Windsor, caregivers who had put their name on a "call-me list" later said that they rarely used it. In Clarendville, caregivers asked to be matched with one other caregiver who was dealing with a similar situation. Although a couple of good matches were created at the beginning, anecdotal feedback has informed us that this initiative hasn't been as helpful as caregivers first hoped. In both cases, caregivers suggested that events where caregiver can meet and socialize together may spark friendships. This can then lead to more "natural" phone support between those people who choose to contact friends who they've met at community events.

Friendly Visiting



Friendly visiting programs match "care receivers" with volunteers as a social opportunity for both parties, and to give the family caregiver a break from caregiving responsibilities. Such programs can create strong relationships and be rewarding for both the volunteer and the person being visited. It also provides the caregiver with opportunity to spend time alone or with other friends and family.

The Network in Springdale that tried to start such a program was very successful in recruiting many volunteers. In the end, the program did not succeed due to lack of people to visit - everyone who was asked assured the coordinator that they were "better off than others who would need the service more." In this case, it may have been the fact that this community, with an exceptional number of churches, may have met its "friendly visiting" needs through other means, including visits from members of the congregation.

As you consider this idea, please note that operating a Friendly Visiting program is a big responsibility. Organizers are responsible for screening potential volunteers and for fully assessing care receivers' needs. In most cases coordinators are hired to provide ongoing support to all program participants. Maintaining such coordinators can be a challenge, as funding often depends on short-term grants.

Despite the responsibilities and challenges, we encourage those communities whose caregivers have expressed interest to explore the possibility of starting a Friendly Visiting program. Find out whether such a program already exists and whether it could be expanded. Encourage other groups in the community such as churches or service clubs to become involved; sharing responsibility through partnerships can lead to success. Talk to groups who have such programs, including the Seniors Resource Centre of Newfoundland and Labrador's Friendly Visiting Program coordinator (709-737-2333). Finally, you may want to find out whether there is potential to apply for grants or to hire student interns.

On-Call Volunteers



Several Regional Caregiver Networks have talked about expanding the idea of a Friendly Visiting program to build a network of volunteers that would help out with any number of tasks, such as yard work, housework, small repairs, shopping, etc. The same cautions and recommendations as described under "Friendly Visiting" apply. Again, the potential benefits are tremendous. Such a program could be very helpful to caregivers and lead to greater feeling of community ownership in supporting family caregivers.

Caregiver Support Groups

Caregivers from across the province have told us that, more than anything, they appreciate being able to meet other caregivers and share experiences. Support groups may already exist in your area, often for caregivers of people with particular illnesses (dementia, Parkinson's, etc).

Please note that support groups don't always exist in smaller communities.

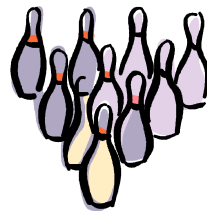


The role of your Network in organizing a support group may vary. A Network member may agree to facilitate such a group directly. You may also want to encourage other community organizations to start a support group, rather than do it yourselves.

In our experience, support groups sometimes work better in larger communities where it is easier for participants to remain anonymous. Caregivers may feel reluctant to "open up" if they worry that another group member, who "lives just down the road" is going to tell someone what they said. For this reason, it can be beneficial to host other kinds of activities where caregivers may meet others, with whom they can talk privately for support.

Caregiver Social Groups

An interesting idea Networks have talked about that has not yet been tried, is organizing social outings for caregivers. Some caregivers have suggested that they have so few opportunities to go out that they want to relax with other caregivers by watching a movie, going bowling or playing cards. In this setting, people can choose whether to talk about issues or, for privacy reasons, to talk on the phone later.



TIP #19 **Make Every** **Caregiver Event a** **Social Outing**

Because it's a challenge for many caregivers to leave their home, your event may be a rare social outing for many. No matter what the activity, make sure to plan to have fun.

Reach Out to Smaller Communities

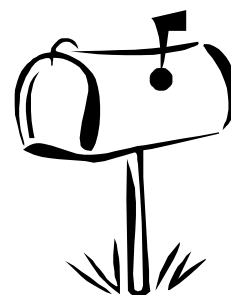
In Newfoundland and Labrador like in other parts of Canada, especially rural areas, it is often assumed that family members will take care of each other as needed. Today smaller families and out-migration have resulted in care receivers having only one family member to rely on. This can lead to an increased feeling of responsibility, especially for a family caregiver who is juggling multiple commitments such as childcare, job demands, etc.

The issues related to decreased family support are made worse in rural communities as there is less access to programs, clinics, recreational opportunities, homecare agencies, organizations and groups. Therefore many rely more heavily on their friends and neighbours, church communities, and other community groups.

The *Caregivers Out of Isolation* program has a provincial toll-free Caregiver Line (1-888-571-2273) and Caring Solutions newsletter that are both available for free to any caregivers in the province.

Some Regional Caregiver Networks have hosted events in smaller communities that surround their "base community." Using small grants and gift certificates donated by gas stations, they have also subsidized transportation costs to enable those living farther away to attend.

The number of caregivers who travel a greater distance to attend events will depend, not only on their transportation, but also on what people in the community are used to. For example, although a caregiver from Mt. Pearl may be reluctant to drive 20 minutes to attend an event in St. John's, the St. Anthony Regional Caregiver Network on Newfoundland's Northern Peninsula hosted caregivers who came from over an hour away!



In addition to hosting events, Regional Caregiver Networks and the provincial program have used provincial initiatives (see page 57, *Caregiver Week*), such as posters, information sheets, displays and local media (see page 41, *Media* and Appendix B) to reach family caregivers. One highlight of our media relations has been with an Inuit radio station in Labrador. Interpreters translate parts of our *Caring Solutions* caregiver newsletter into Inuktitut and broadcast relevant section to Inuit families living on the northeast coast of Labrador. In this way, we hope to reach Inuit caregivers with material that is not only in their own language, but also culturally appropriate.

Technology can also enable caregivers and community partners from more remote communities to participate in caregiving initiatives. Low-cost teleconferencing is now available so can join meetings by phone if they can't attend in person. Community Access Programs based at local library branches, etc. provide Internet services to a greater number of people. The contribution and insights of people living in rural communities is invaluable to your initiative.

TIP #20

Find Ways To Include People Who Join Meetings By Phone

Make sure that your agenda includes opportunities for those by phone to report. Encourage them to ask questions as much as possible. Finally, it can help to contact them individually before and after the meeting to make sure they feel included.



Provide 1-on-1 Support to Caregivers



Quite often caregivers experience social isolation, as limited time and energy can cause caregivers to lose touch with their friends. Even family members such as siblings and cousins aren't always as close or supportive as they could be. Other caregivers prefer to talk to someone who isn't directly involved in their situation. Regardless of the situation, numerous caregivers contact us for one-on-one support.

For one-on-one support, caregivers who call the Newfoundland and Labrador Caregiver Line are often referred to Regional Caregiver Network members associated with an organization in their area. These professionals also meet caregivers at local Network-organized community events, where trust is established.

Some Network members offered to support caregivers via the phone. These Network members, especially those who are caregivers or former caregivers, talk to caregivers from home, giving much-needed encouragement and advice.

Promote Policy Change

Addressing Individual Problems

You may need to help caregivers determine who has the power to make changes that address the issue that they're dealing with. Often caregivers who are frustrated just need guidance on where to turn. In order to contest a decision about subsidized homecare, for example, they should talk to an intake supervisors in their health region. If the caregivers want legislation to be changed or new funding programs to be established, you can direct them to their M.H.A. or M.P. If you're in Newfoundland and Labrador, call the Caregiver Line for ideas.

Addressing Community Issues

Organize a meeting every so often in order to give local caregivers a chance to talk about their issues and make suggestions for how to address these issues. We suggest that the following meeting format may help:

- Provide information about local resources, making sure that you recognize that there are not enough resources for caregivers. Even if you don't mean to, you can sometimes give caregivers the impression that you think there are lots of community supports for them - most caregivers we know would disagree!
- It is also helpful for some caregivers to hear about the kinds of developments taking place to support caregivers both provincially and nationally. This information should feel relevant to their day-to-day experience, so try to use specific examples.
- Facilitate a discussion on the gaps in community supports and what needs to be done for caregivers in your area. You might want to start with the main ideas brought up during planning sessions (see page 24 of *Getting Started*). Allow lots of time for feedback.

- ❑ Encourage the caregivers to think creatively - they may have suggestions on how best to deal with the challenges that face them.
- ❑ Keep in mind, decision-makers will respond better to proactive suggestions, than to frustrated complaints.
- ❑ Make sure that the above discussion moves beyond the issues/concerns to **do-able** local solutions. **Don't set impossible goals!** Encourage everyone to think of little steps and, eventually, limit yourselves to two or three priorities. Working with the groups' suggestions, you may also want to suggest ideas from page 27-58, *Regional Caregiver Network Roles*.
- ❑ Circulate a second sheet for caregivers to sign up if they're interested in meeting again to look into this further. If there is an organized Caregiver Network in your community, these people may want to join.
- ❑ As with your planning meetings, leave people with a clear sense of what you're going to do after the meeting.

TIP #21

**In Policy Work, Use Personal Stories
to Illustrate your Points**

Even if you have succinct well-researched recommendations, caregivers' stories will make the greatest impact.

Reviewing Policies

As you discuss issues and ideas to address them, try to identify specific policies that relate to the issue. Be clear about how the policy affects family caregivers and, if appropriate, what changes could be made and how the changes could affect people's lives.

You will need to determine:

- Whether the policy is federal (i.e. federal taxes), provincial (i.e. provision of subsidized home support), municipal (i.e. bus routes, accessible buildings), or private (i.e. how a business operates)
- Who has the power to change the policy
- Who (a person or committee) do you need to work with to influence whether the policy is reviewed and, potentially, changed.

Presenting Recommendations

If you are seeking change, it is essential that you communicate your ideas with those who have the power to make changes: Regional Health Boards, town councils, business owners/managers, provincial M.H.A.s (called M.L.A.s and M.P.P.s in some provinces), federal M.P.s., etc. Keep your message clear, focused and consistent. Write letters, make phone calls and, if possible, meet with them in person.

TIP #22

Use Statistics

Decision-makers will also want "evidence." Be prepared to back up your points with statistics whenever possible (see Appendix C's *Fact Sheet* for some caregiving statistics).

Working Together with Provincial & National Organizations



In Newfoundland and Labrador, Regional Caregiver Networks work with the *Caregivers Out of Isolation* program. For provincial and federal issues, especially those that have been identified in several regions, it is helpful to contact the appropriate departments as a provincial coalition, rather than individual Networks.

Provincial Caregivers Week

In 2004, the Regional Caregiver Networks decided to coordinate their activities and increase community awareness raising efforts during one particular week: Newfoundland and Labrador Caregiver of Family & Friends Week. This provincial approach worked well and has become an ongoing annual event. It involves the efforts of many people: (1) the provincial government proclaims the week (see Appendix E: *NL Caregiver Week Proclamation*), (2) our province's Regional Caregiver Networks offer events for caregivers during this time, and (3) both provincial and regional groups promote caregiving in the media. These coordinated efforts are more efficient, as Networks share materials, and all benefit from simultaneous media coverage of the events and issues.

Organize An Event For Caregivers

Most Regional Caregiver Networks host a Caregiver Day Away or other activity during Caregiver Week. This year, one Network focused on promoting their Day Away during Caregiver Week in order to capitalize on increased media coverage. They then hosted the event 2 weeks later; this approach also worked quite well and attracted many new caregivers.

Involve Local Businesses

The Humber Valley Regional Caregiver Network experimented recently with the idea of, not just hosting events, but inspiring others in the community to recognize caregivers during Caregiver Week. With the Network's encouragement, a local coffee shop hosted a breakfast for caregivers. The coffee shop provided the space and coffee, and an M.H.A.'s office provided muffins and snacks. The Network's role was to register interested caregivers ahead of time and to welcome them to the event.

This idea could be taken even further. What if grocery stores offered a 10% discount to caregivers during Caregiver Week? What if service clubs hosted a tea, or a dinner? What if flower shops offered one free carnation to their caregiver customers? Caregivers could obtain a Caregiver ID card from their Network or provincial organization to qualify them for such discounts and/or events. The possibilities are endless!

Contact the Media

Contact local, provincial and even national media. Tell them about your plans, or to tell a local caregiver's story. As described above, the province-wide exposure provides excellent momentum. For more on how to do this, see page 41 *the Media* and Appendix B.

Involve Well-Known Local People

... by asking them to sign a Caregiver Week proclamation, to recognize caregivers at local events, or by donating towards food costs, transportation/respice costs or door prizes. Potential people may include local politicians, celebrities or other well-known individuals.

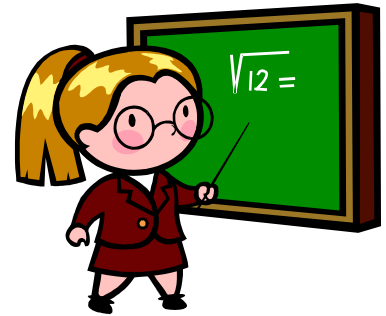
Caregiver Appreciation Cards

In 2005, the Regional Caregiver Networks helped to launch an incredible initiative that was started by a group of caregivers in Forteau, Labrador. Together, they created a Caregiver Appreciation Card and provided it at no cost to the general public through displays at local businesses. People in the community were encouraged to take a card and give it to a caregiver they knew. The card recognized caregivers' efforts and provided space for the card-giver to offer their support (see Appendix F: *Caregiver Appreciation Cards*).

Based on the above experience, we have some ideas of how to make such an initiative even more successful. We plan to work more closely with local vendors who display the cards, so that we can have clearer feedback from them after Caregiver Week. Ideally, we will look for the support of one or two larger businesses such as supermarkets, pharmacies or banks, who could display the cards at branches across the province. If you try to do this, keep in mind that the businesses you choose should have branches in rural areas too.

Overall, the initiative was a great success, which also gave a good focus to much of our media work. The card was a great tool to promote the idea that everyone can play a role in supporting caregivers. We were especially pleased when the Alberta Caregivers Association decided to use this idea for caregivers in that province!

LESSONS LEARNED



Sharing Responsibility

As with all volunteer initiatives, it is important to "share the load" as much as possible between Network members. If each member feels that they can contribute their particular skills, they will be more likely to remain committed to the group. Try to make sure that all the members of the team feel good about helping to achieve your group's goals together.

Those who are participating as employees of organizations such as the Regional Integrated Health Authorities or not-for-profit organizations may find it difficult to juggle commitments; therefore, we recommend ensuring that your group includes a balance of volunteers, and professionals. Be sensitive to the fact that members who are caregivers may be busier at some times than others. Because our efforts are meant to improve, not add stress to their caregiving experience, we have to be particularly careful not to have unreasonable expectations of caregivers.



Avoid Volunteer Burnout!

Particularly in rural communities, the same volunteers are supporting several community initiatives. These people are often the backbone of the community. While it is wonderful to have "doers" supporting your Network activities, make sure that you have reasonable expectations of them, that they feel comfortable setting limits when necessary, and that you show them regularly your appreciation for all their hard work.



Leadership

In addition to shared responsibility, it helps the Network immensely to have 2 or 3 members who are driving the group forward. This may be a professional who can work for the Regional Caregivers Network as part of their job, or a caregiver who is especially passionate about your shared goals. Ideally, even if the leadership is shared; if the "one key person" should become sick, for example, the Network's work will continue.

Some Networks have chosen to designate a Chair and/or Secretary, whereas others rotate these positions every month or two. Either way, you will need someone to act as a contact person with other Networks in the province, and with caregivers who are interested in connecting with your Network. It is important to update your provincial organization (e.g. *Caregivers Out of Isolation*) and other Regional Caregiver Networks as these roles change.

Maintaining Momentum

All of the above factors should result in your Regional Caregiver Network maintaining its momentum, though keep in mind there will always be ups and downs.

Another way to make sure your Network stays on task and motivated is to have regular interactions with caregivers. Not only is it important that caregivers participate in regular Network meetings, it helps Network members to feel rewarded when they see caregivers benefiting from their efforts. We recommend trying to host simple activities as often as possible (within reason!) not just because caregivers are asking for it, but also because it helps to make sure we feel like we are making a difference in people's lives!

TIP #23

Share positive feedback

It feels good to know you're making a difference in caregivers' lives - in meetings, highlight positive feedback you've received.

TIP #24

Keep it fun!

The Springdale Regional Caregiver Network goes out for a meal every year.

CONCLUSION

In Canada, as supports to family caregivers are starting to grow, we are very pleased to see how much has been achieved already by the Regional Caregiver Networks in Newfoundland and Labrador. These groups work with very little financial resources or paid staff and a geography and climate that can be tremendously challenging. **Based on their passion for supporting family caregivers, people across this province have created an approach that is unique in Canada.**

We hope that our initiative will continue to expand, in the number of Networks established and linked across the province, as well as in the scope of the work that they do. There's no question that there is a great need. As our population ages, and as fewer family members are available to share caregiving responsibilities, there will be an increasing demand for other kinds of caregiver supports. Although the Regional Caregiver Networks cannot meet all the support needs of caregivers, evaluations show that they have a significant positive impact. We hope that in future years we will reach even more caregivers and find even better ways to support them.

Good luck in all that you do! We look forward to working together with you and with others across the country towards our shared goal: that family caregivers everywhere have more of the support and recognition that they deserve.

**How We Grew: Regional Caregiver Networks in NL
Caregivers Out of Isolation, 2006**

APPENDIX A - *Tips*

Note: these tips can be found in the shaded tip boxes throughout the Guide.

**How We Grew: Regional Caregiver Networks in NL
Caregivers Out of Isolation, 2006**

TIP #1

Enable caregivers to join Network planning

- Schedule meetings based on the availability of interested caregivers (e.g. afternoons)
- Try to supplement costs of replacement care (also known as "respite")
- If needed, help with transportation needs/costs
- Ensure that discussions are in plain language, so that everyone feels included

TIP # 2

If you choose to have a student, we suggest...

- Set clear achievable goals, re-evaluating regularly.
- Set up a clear system for supervision. The Avalon East Network has set up a supervisory team.
- Share responsibility - In the Humber Valley Network, one person prepared the proposal, another agreed to host a student at their organization, and two more agreed to supervise and deal with administrative tasks.
- As part of the orientation process, ask caregivers in your area to talk to the student about what it's like to be a caregiver. You may need to emphasize that this is not for "counseling," but for caregivers to share their expertise and experience.

TIP #3

Make sure that caregivers direct the Network's objectives

Always try to focus on what caregivers in your region would like you to do. If you need more input, organize a community meeting to ask them.

TIP #4

How to introduce the idea of Regional Caregiver Networks:

During a planning meeting, you should tell participants that other Networks exist. Nevertheless, wait until your group has discussed local issues and possible solutions before talking in detail about other Networks' activities etc.

TIP #5

Set a regular meeting schedule

You'd be surprised how much time and energy can go into setting a date that all Network members can agree on. We highly recommend choosing a day, such as "the first Tuesday of the month from 2 - 4 pm." Keep in mind that weather and other factors may result in the need to re-schedule.

TIP #6

Always Respect Confidentiality

Giving event invitations to organizations helps avoid breaching confidentiality. Instead of asking them to give you their mailing lists, they are able to give invitations directly to their clients who they think might be interested in your event.

TIP #7

Try holding an event where "care receivers" are also invited.

Sometimes your group may want to open a social event to all caregivers and those they care for. This can be fun for all involved, and provide an opportunity for caregivers to introduce others to some of the most important people in their lives: their family member/friend.

TIP #8

Have fun!

Keep in mind that many family caregivers rarely take time for themselves. Your event might be the first "break" they've had in weeks. Invite local musicians and performers, offer door prizes, have a fun skit (maybe with a caregiving theme), etc. Try to make sure that everyone leaves with a smile on their face.

TIP #9

Recognize the tremendous role of caregivers again and again and again and again... (you get the idea!) This will be new to many caregivers, who are often impressed by all that others do, but don't recognize their own contribution.

TIP #10

Set realistic goals

If you make plans for the future, keep them DO-ABLE - it's easy to get wrapped up in the enthusiasm and power of the day, and set lofty goals that are impossible to achieve. As organizers, don't make promises that you can't keep.

TIP #11

Think small and often

Caregivers suggest that, if possible, they would like Networks to hold several smaller activities versus one large-scale activity annually. In our evaluator's words, "*think small and often*"

TIP #12

Share responsibilities

When you are planning an activity, especially a larger event such as the Day Away, you may want to divide into sub-groups. All members of the Avalon East Regional Caregiver Network work together to organize presenters, displays and volunteers. They also form two sub-committees: (1) donations and (2) media & communications.

TIP #13

At a Day Away, you may want to focus on fun, relaxing activities

Because the Day Away is an opportunity for some caregivers to "get away from it all" you might want to save more serious topics, like the availability of services, for a separate session. At your Day Away, we recommend circulating a sign-up sheet for those who are interested in attending future information sessions.

TIP #14

For ideas of topics...

... ask local caregivers: at your events, through announcements in the local newspaper, and through the provincial caregiver newsletter, etc.

TIP # 15

At presentations, allow lots of time for questions.

You may want to have prepared a few questions to get the ball rolling, in case participants are shy at first.

TIP #16

For a Caregiver Panel, variety is important.

The audience will probably benefit more if at least one person on the panel has a similar situation to theirs. Your panel should feature both male and female caregivers, including those dealing with aging issues, mental illnesses, and disabilities. Include caregivers who support people in their home as well as in facilities. Former caregivers are often very well-received, as they have usually had time to reflect on their experiences.

TIP #17

When possible, try to approach media people who you know

You can send general media releases, P.S.A.'s (Public Service Announcements) and Fact Sheets to local media outlets (see Appendix B), but for better coverage it sometimes helps to directly approach people you know. Find out who among your Network has media contacts and ask them to follow up.

TIP #18

Be sensitive when dealing with caregivers and the media.

The most interesting story is often the caregiver's own personal story. Understandably, caregivers can be reluctant to share this kind of information, sometimes because they don't want the person they're supporting to feel like a burden, or for others to perceive it that way. A caregiver may appreciate the opportunity to review a story before it airs, although this is often not possible due to time constraints. Reassure the caregiver repeatedly that they don't need to talk about anything they feel less than 100% comfortable with.

TIP #19

Make every caregiver event a social outing

Because it's a challenge for many caregivers to leave their home, your event may be a rare social outing for many. No matter what the activity, make sure to plan to have fun.

TIP #20

Find ways to include people who join meetings by phone

Make sure that your agenda includes opportunities for those by phone to report. Encourage them to ask questions as much as possible. Finally, it can help to contact them individually before and after the meeting to make sure they feel included.

TIP #21

In policy work, use personal stories

To illustrate your points

Even if you have succinct well-researched recommendations, caregivers' stories will make the greatest impact.

TIP #22

Use statistics

Decision-makers will also want "evidence." Be prepared to back up your points with statistics whenever possible (see Appendix C's *Fact Sheet* for some caregiving statistics).

TIP #23

Share positive feedback

It feels good to know you're making a difference in caregivers' lives - in meetings, highlight positive feedback you've received.

TIP #24

Keep it fun!

The Springdale Regional Caregiver Network goes out for a meal every year.

**How We Grew: Regional Caregiver Networks in NL
Caregivers Out of Isolation, 2006**

APPENDIX B - *Setting Goals & Objectives*

**How We Grew: Regional Caregiver Networks in NL
Caregivers Out of Isolation, 2006**

GOAL _____

OBJECTIVE	STEPS NEEDED	TIMELINE	TEAM MEMBERS & TASKS		OTHER COMMUNITY MEMBERS & TASKS	

The following is an example of how you might use this table:

GOAL - To increase community awareness about caregiving in Carbonear

OBJECTIVE	STEPS NEEDED	TIMELINE	TEAM MEMBERS & TASKS		OTHER COMMUNITY MEMBERS & TASKS	
To have 2 articles about caregiving published in the Compass	Brainstorm topic ideas	May 13	All group members	Meet to brainstorm topic ideas	Reporter: Mary Smith	Join brainstorming meeting
	"Pitch" ideas to editor	May 15-21	Judy	Call editor to review ideas		
	Involve local caregivers	May 15-28	All group members	Talk to caregivers you know about possibly being interviewed		
	Write articles or meet with a reporter	May 22-28	Joe & Melissa	Write one article each, based on selected topic ideas or be interviewed by Mary Smith	Reporter: Mary Smith	Interview Network members and local caregivers or write articles on caregiving
To speak on VOCM's Open Line	Call Open Line	June 5	Donna	Announce local caregiver meetings	Sheila Doreen	Call Open Line about their roles as caregivers and why they enjoy meeting others and working with the local Network
To present to 2 or more local service clubs	Design presentation	June 5 - 9	Judy Denise	Create presentation Edit presentation		
	Arrange dates	June 5 - 9	Donna	Contact local service clubs		
	Give presentation	June 12 - 30	Phyllis & Joe	Bring materials, give presentations & answer questions		

APPENDIX C - *Media Kit*

**How We Grew: Regional Caregiver Networks in NL
Caregivers Out of Isolation, 2006**

Media Kit:

The following is an example of a P.S.A. (Public Service Announcement). It can be emailed or faxed to local radio and television stations, as well as newspapers.

Before sending this to the media, we recommend you try to send it to the proper contact (i.e. not just the local CBC radio, but the CBC morning show host: community announcements) in the right format (e.g. 30 words or less)

Public Service Announcement

Monday April 4th, 2-4 p.m.

Come join a planning session on April 4th at 2 pm at the Clarenville Lions Club for a community event to be held in late April to recognize and support unpaid caregivers of family/friends. All individuals and community groups with ideas or a little time to contribute are welcome. For more information, call Erin at the Caregiver Line: 1-888-571-2273.

-end of announcement-

Contact person:
Erin Holland
Project Coordinator,
Newfoundland and Labrador Caregivers Out of Isolation
C/o the Seniors Resource Centre
1-888-571-2273

An excellent resource for developing these kinds of materials is available on-line through the Newfoundland and Labrador Community Services Council at: www.envision.ca Note: click on "Media Room" under "News and Calendar of Events" on the top right hand corner of your computer screen. You will find media contact lists, as well as guidelines for working with the media.

On the page that follows, you will see an example of two media releases. In particular, please note the following:

- ☆ The most important information is at the beginning.
- ☆ You should include quotes, preferably from someone who is not a member of your group - realistically, it is much easier to compose your own quotes.
- ☆ Use a catchy title.

For Immediate Release:

April 23, 2005

Clarenville Area Supports Invisible Heroes

Event being planned locally to recognize those providing unpaid care to family and friends.

On April 27th at 2 - 4pm there will be a meeting at the Clarenville Lions Club to plan a luncheon for unpaid caregivers of family and friends. Usually these caregivers focus on providing care and support to others. Soon, for at least one afternoon, that role will be reversed. Family caregivers in the area will have a chance to come out and have people serve *them* and think about *their* needs.

Those people who have met so far have talked a lot about the importance of recognizing the many people in our community who are giving unpaid care and support to friends and family members. Not only will the planning session on the 27th explore ways to recognize caregivers, there will also be discussion about how to give caregivers a chance to meet with others who are in their shoes, to connect them with community resources, to have a little fun, and to give them a break from their daily responsibilities.

“We will welcome anyone who wants to be a part of putting this together,” says Erin Holland, who is with Caregivers Out of Isolation, the provincial program that has facilitated the development of this group. “We need people to contribute ideas and to help out with small tasks. Ideally, we’d like to see a lot of the community involved, even in staying with the person who receives care so the caregiver can come out for the day.”

“This is going to be a fun day for everyone,” Erin predicts. “I think we’re all excited for the chance to give something to those who do so much for others. It feels great knowing that we might make what can be challenging situations a little easier, even if it’s just for a day.”

Anyone who wants to be a part of the April 27th planning session can call Jamie Winter-O’Keefe at 428-4690 or Erin Holland at 1-888-571-2273. The toll-free number is the Caregiver Line, which is also available for support and information to family caregivers in the province. Caregivers signing up for the luncheon should call Yvonne at 428-3863 or Margaret at 428-8080

Media contacts:

Jamie Winter-O’Keefe
428-4690

Media Release
For Immediate Release

WHO CARES?

Newfoundland and Labrador celebrates “Caregivers of Family & Friends Week”: Oct. 3 – 9, 2005

(September 27, 2005 – St. John’s) Who cares? More than 14% of Newfoundlanders and Labradorians do, providing unpaid care and support to their family members and friends who are dealing with an illness or disability. In Canada, care provided by caregivers of family & friends would cost over \$5 billion annually if provided by the formal health care system. In recognition of these often-invisible heroes, the Government of Newfoundland and Labrador will be declaring the 2nd annual Caregivers of Family & Friends Week.

During Caregiver Week and throughout the month of October, Regional Caregiver Networks will host events across the province, such as a “Caregiver Day Away,” “Tea & Talk,” and various information sessions. The best part of any event, according to the caregivers who attend, is the chance to meet others who share the joys and the challenges of caregiving. Events will be held in Corner Brook, Meadows, Springdale, Grand Falls-Windsor, Twillingate, Clarenville, St. Anthony and St. John’s.

Ross Wiseman, MHA for Trinity North and Parliamentary Secretary to the Minister of Health and Community Services, says it is important that the general public acknowledges and commends caregivers and the important role they play. “Caregivers are vitally essential to our communities. Government recognizes their important contribution and we are committed to ensuring that caregivers in the province are acknowledged and valued.”

According to the Caregivers Out of Isolation project, Caregiver Week is also an excellent opportunity for the general public to reach out to caregivers. Because the demands of caregiving can result in caregivers feeling isolated and exhausted, people are encouraged to support the caregivers in their communities. During October, there will be a province-wide

**How We Grew: Regional Caregiver Networks in NL
Caregivers Out of Isolation, 2006**

challenge to show our support by offering to spend time with, make a meal or do odd jobs for caregivers and their families. Caregiver Appreciation Cards will be available, free, through many outlets in various communities across the province.

For more information about the events being held during Caregivers of Family and Friends Week, or about the Regional Caregiver Networks and the Caregivers Out of Isolation project, please call the Caregiver Line at 1-888-571-2273.

Media contact:

Erin Holland,
Project Coordinator
Caregivers Out of Isolation project
c/o the Seniors Resource Centre of Newfoundland and Labrador
(709) 737-2333
280 Torbay Road, Suite W100
St John's, NL A1A 3W8
www.caregiversNL.ca
caregivers@nf.aibn.com



"If the health-care system were a plant, family caregivers would be its roots: invisible, fragile and vital." Silver Donald Cameron, 2003.

APPENDIX D - *Fact Sheet*

**How We Grew: Regional Caregiver Networks in NL
Caregivers Out of Isolation, 2006**

Caregivers Out of Isolation Project
at the Seniors Resource Centre
280 Torbay Road, Bally Rou Place, Suite 100
St. John's, NL A1A 3W8
Tel: (709) 737-2333 Fax: (709) 737-3717



BACKGROUNDER

Caregiver of Family & Friends October 2004

- In 2001 about 14% of adults aged 18 to 64 in Newfoundland and Labrador cared for others without pay on a regular basis (*From the Ground Up*).
- Recent research by I.H.R.D. in the *Caregivers Out of Isolation Newfoundland and Labrador Caregiver Survey* (2004) shows that of those interviewed:
 - ⇒ **Most caregivers are women** (91%) and **most of those receiving care are 70+** (>60%)
 - ⇒ **Caregivers sacrifice much of their time providing support and care for others** (91% of those interviewed recently are caregivers 7 days a week, 66% provide support 24 hours a day).
 - ⇒ **Caregiving is often a long-term commitment** (59% of those interviewed had been caregivers for more than 5 years).
 - ⇒ **When inadequate supports are available, caregiving can affect quality of life** (only 32% described the quality of their lives as pretty good or excellent – most of these caregivers credited formal and informal supports).
- 90% of all personal care in Canada is provided by caregivers (Guberman, 1999. *Caregivers and Caregiving*. Health Canada: Ottawa);
- The services caregivers provide in Canada would cost over \$5 billion per year if delivered by the paid workforce (Keating, 2001, *Economic Impact of Health, Income Security, and Labour Policies on Informal Caregivers of Frail Seniors*);

Supports available in Newfoundland and Labrador include...

The Caregiver Line: 1-888-571-CARE (2273)

Compassionate listening and advice on available resources

Caring Solutions Newsletter: free, quarterly, full of tips and support

Regional Caregiver Networks: have been created right across the province in St. Anthony, Springdale, Grand Falls-Windsor, the Humber Valley and Avalon East. The Networks consist of caregivers, community groups and agencies that are in contact with caregivers. They host events for caregivers, raise community awareness and are exploring other ways to support caregivers in their communities. Program organizers hope to set up similar Networks in the coming months to reach caregivers in other areas of the province.

**How We Grew: Regional Caregiver Networks in NL
Caregivers Out of Isolation, 2006**

Appendix E: *Caregiver Icebreaker*

**How We Grew: Regional Caregiver Networks in NL
Caregivers Out of Isolation, 2006**



Caregiver Bingo

Find someone who...

Provides care for their husband or wife:	Provides care for a relative:	Is not a caregiver:	Has gone for a walk this week:
Has more than 4 children:	Has a dog:	Is attending his/her first family caregiver event:	Is supporting someone who lives in a facility:
Is celebrating their birthday this month:	Provides care for an adult child:	Is pleased to be here today:	Is a member of a Regional Caregiver Network or committee:
Provides care for a friend:	Is a former caregiver:	Has had at least one good break this week:	Shares their caregiving responsibilities with someone:

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Caregivers Out of Isolation, 2006**

APPENDIX F – *Planning a Caregiver Day Away*

**How We Grew: Regional Caregiver Networks in NL
Caregivers Out of Isolation, 2006**

Day Away "To Do" List

Please note: this list was created by the Avalon East RCN, 2004

Early in the Year:

- Contact the Wellness Coalition [or other potential funding sources] in early March
- Discuss in which community the event will be held.
- Organize date and location for "Day Away."
- Organize meal.
- Determine how to pay for meal.

Donations:

- Update donation letters (for door prizes, grab bags, taxi gift certificates).
- Organize volunteers to fax and call for donations.
- Call for donation of plastic bags for grab bags
- Fax donation letters.
- Call back businesses about donations.
- Contact florist to request carnation donation.
- Request donation of cake.
- Keep a list of donations received and who donated them.
- Update and distribute thank-you letters.

Communications:

- Contact NTV. Contact "Out of the Fog" and Channel 9.
- Call Open Line and CBC radio soapbox (Wed. afternoon).
- Prepare and distribute public service announcement and newspaper article.
- Update invitations and send invitations.
- Prepare registration sheet.
- Keep track of registration with wait list.
- Call caregivers to confirm attendance.
- Update posters and distribute them.

Plans for the Day:

- Confirm numbers for meals
- Contact presenters/massage therapists/displays(i.e. OT, PT, etc)/M.C.
- Contact entertainers
- Plan agenda for "Day Away."
- Make a nice copy of the agenda.
- Organize transportation for caregivers who need it.
- Prepare nametags (Network members and caregivers).
- Network members bring contributions for grab bags.
- Prepare grab bags and door prizes.
- Prepare evaluation forms.
- Optional: Prepare decorations for tables.

**How We Grew: Regional Caregiver Networks in NL
Caregivers Out of Isolation, 2006**

APPENDIX G - *NL Caregiver Week Proclamation*

**How We Grew: Regional Caregiver Networks in NL
Caregivers Out of Isolation, 2006**

Proclamation: 2005 Newfoundland and Labrador Caregivers of Family & Friends Week

Caregivers are the backbone of our health and community care system, providing unpaid care and emotional support to family members and friends, including seniors, persons with intellectual and physical disabilities, and those affected by progressive and chronic illnesses;

Caregivers are key partners in the formal health and community services system, as well as co-clients, with needs distinct from those to whom they provide care;

Caregivers are integral members of our communities, demonstrating values of love and compassion, strength of spirit, and selflessness;

We acknowledge the strength of rural caregivers who, despite facing unique challenges such as traveling greater distances for services and supports, remain committed to those they care for;

We acknowledge the importance of community support for caregivers and those they care for, by friends and neighbours, by employers, by service providers and by governments of all levels;

In recognition of the invaluable contribution of caregivers to our communities, I Ross Wiseman, declare October 3 – 9th, 2005 the 2nd annual Newfoundland and Labrador Caregivers of Family & Friends Week.

Ross Wiseman

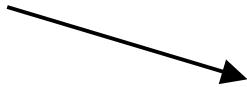
M.H.A., District of Trinity North
Parliamentary Secretary to the Minister of Health & Community Services

**How We Grew: Regional Caregiver Networks in NL
Caregivers Out of Isolation, 2006**

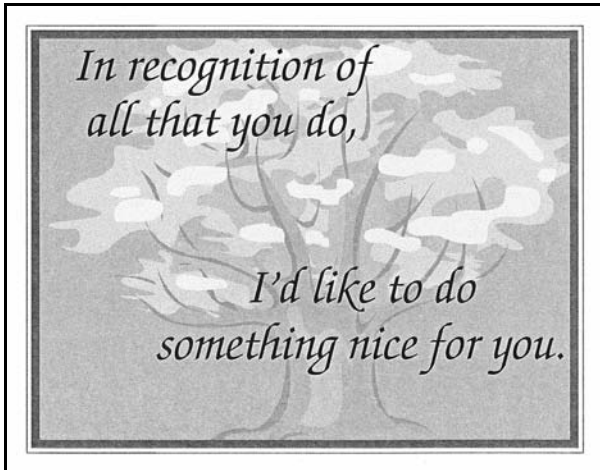
APPENDIX H - *Caregiver Appreciation Cards*

**How We Grew: Regional Caregiver Networks in NL
Caregivers Out of Isolation, 2006**

The display was a very basic, coloured paper bag.



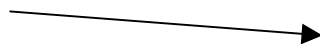
How We Grew: Regional Caregiver Networks in NL
Caregivers Out of Isolation, 2006



Caregiver Appreciation Card,
front cover



Caregiver Appreciation Card,
inside



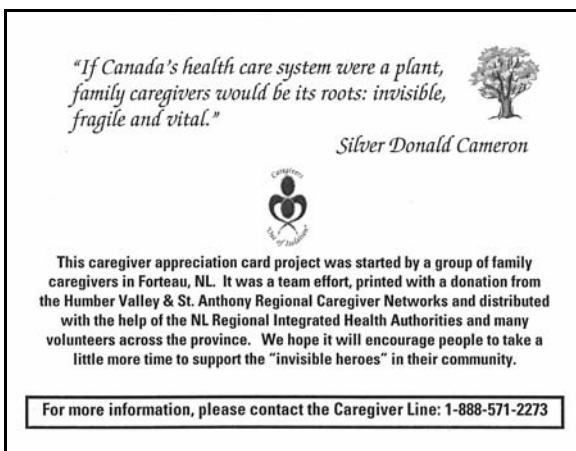
I would like to:

- Assist with odd jobs
- Bring your family a meal
- Spend time with you or your family
- Spend time with _____ in or out of the home
(person receiving care)
- Other: *(please write your own ideas in the space below)*

Let me know if this would be helpful. Please contact me to arrange a time that works for you.

_____ (card-giver's name)

_____ (card-giver's phone number)



Caregiver Appreciation Card,
back cover

