

Time For Caregivers

A Survey of Unpaid Caregivers in the Wolfville Area

A project of Churches and Parishes of
The Wolfville Area Inter-Church Council

Funded by the Eastern Kings Memorial Health Foundation

Survey conducted by Jennifer Longley
Oct. 2004 – March 2005

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SUMMARY

Having recognized that the growing number of caregivers in the Wolfville area have needs which for the most part are not being recognized or met by church or community, a project was undertaken in order that all might better understand our caregivers and their situations. Funded by a grant, an ecumenical group representing all local churches hired a researcher to interview as many caregivers willing to participate in the project as possible within the allotted five month period. Caregivers generously gave of their limited time and energy to provide valuable information and insight into their situations and needs. The interviews generated hope that there are those who care and that there might be those willing to help the caregivers. The information provided by the caregivers identified numerous ways in which caregivers could, and should, be helped.

INTRODUCTION

Definition of Caregiver

A “caregiver” was defined as a person who provides regular assistance to an individual in need of care. While a caregiver may be part of either the informal or formal care sector, this project focused on the informal caregiver who provides unpaid care and support to a family member, friend or neighbour. Those receiving care may live with the caregiver, may still be in their own homes or may now be residents of long-term or special care facilities or patients in hospitals.

Wolfville Baptist Church Initiative

In February 2004 a small group in the Wolfville Baptist Church concerned about unpaid caregivers met as “Time for Caregivers”. They compiled a list of those they felt were in that category. They met with some and phoned others. They felt much more needed to be known as to the felt needs of unpaid caregivers, and how the church could support them.

Project Proposal

In March 2004 the Wolfville Baptist group prepared a project proposal for submission to the Eastern Kings Memorial Health Foundation. The proposal was for a comprehensive survey of all unpaid caregivers in the Wolfville area, and over a 12 month period to begin a sustainable program of support for those caregivers. (Appendix A.) The Wolfville Area Inter-Church Council endorsed the proposal.

Eastern Kings Memorial Health Foundation Funding

In April the Foundation granted \$6,000.00 for the project, half of what had been requested. The Wolfville group revised its objectives and submitted the revised project proposal to the Inter-Church Council and members churches. (Appendix B) The following member churches and parishes of the WAICC endorsed the project: Port Williams United Baptist Church, St. Francis of Assisi Parish (Catholic), St. John’s Anglican Church, Wolfville Pastoral Charge of the United Church of Canada, and the Wolfville United Baptist Church. As each member church or parish agreed to participate in the project, they named their representatives on the management group.

Management Group

The members of the Time for Caregivers Management Group were: Maggie Kenny (St Francis Catholic Parish), Ann Watson (St. John’s Anglican Church), Doreen Tillotson (United Pastoral Charge), Roger Cann (Wolfville Baptist) and Sylvia Burgher, (Port Williams Baptist). They first met on the 21st of June with Roger Cann as convenor, and Maggie Kenny the recorder. The Society of Friends (Quakers) endorsed the project and provided contacts with caregivers in their fellowship.

At subsequent meetings (July 19, August 2 & 9), the Group adopted Interviewer Guidelines (Appendix C), prepared a Consent Form (Appendix D), the Interview Outline (Appendix E) and framed a Job Description for the Researcher (Appendix F).

Appointment of Researcher

In September the Management Group advertised for applications for the position of researcher in local and community newspapers. After an interview, the Group appointed Jennifer Longley to begin the survey in October 2004.

Publicity

The prime avenue for publicity on the survey was through announcements in the participating parishes and churches. The Kentville Advertiser included an article on the survey in November, and brief notes were included in community papers in October.

OBJECTIVES

The original proposal was for a series of comprehensive interviews of unpaid caregivers in the area over 12 months. (Appendix A) The results would be periodically shared with the Management Group, and by them to the supporting churches and parishes. It was anticipated that partners in the health field and community based organizations would be informed of the progress of the survey and encouraged to play a part in the future programming.

Once it had been determined that only half of the proposed funding would be available, the objectives were modified. The desire to compile a bank of resources in print and on video cassette, and make them available through the Health Quest library of the Health Centre was dropped.

The objectives of the project as stated in April were:

1. Interview informal caregivers in the community, and document their needs; physical, emotional and spiritual.
2. Work with partners such as HomeCare, the VON, the EKM Community Health Centre, the Mental Health Department of the Annapolis Valley Health Authority, Community Links, and the Family Caregivers Association of Nova Scotia, to provide resources to caregivers in our community.
3. Propose to our partners and the ecumenical community at large, specific service programmes and personnel support for informal caregivers in our midst, matching their physical, emotional and spiritual needs.

The Action Plan of the original proposal included the following vision:

“In the first year the management group will fashion an appropriate design for the program which can be sustained by the churches on their own. Previously the Wolfville Area InterChurch Council established InterChurch Housing, and Meals on Wheels, which are sustaining. There is confidence the same can happen for “Time for Caregivers”.”

In December 2004 the Management Group applied for a New Horizon grant from the Federal Government. The project proposal was endorsed by the Wolfville Area InterChurch Council and six member bodies of the WAICC. The proposed program would have supported and built on current activities of unpaid caregivers through visitation, respite for those caregivers, and providing resources (print, video, an information hot line, and interactive web site). The proposal was turned down.

METHODOLOGY

Interviewees

Those interviewed were affiliated with one of the churches or parishes which are members of the Wolfville Area Inter-Church Council, or were resident in Wolfville, or an adjoining community.

Arranging Interviews

Members of the Management Group provided the researcher with the names of caregivers they had contacted about the study and who had agreed to be interviewed. One church provided the researcher with a list of those persons felt to be caregivers but had not checked with them about willingness to participate. The Quaker Meeting did not have a representative on the Management Group. The researcher contacted two members of their Meeting to obtain the names of their caregivers.

In all instances the caregivers were contacted by phone by the researcher, their questions about the research project answered, and an interview time and place convenient to the caregiver was scheduled. One caregiver called the researcher in response to information a friend had given her.

In several instances the researcher spent as much time or more on the phone with caregivers declining an interview as would have been spent in an interview. They did not feel able to be interviewed in person for a variety of reasons. The Management Group encouraged the researcher to include points made by these caregivers which pertained to the study in the survey data.

With at least half of all caregivers contacted it was necessary to phone them more than once in order to schedule an interview. Many phoned the researcher to reschedule or cancel a scheduled interview time.

Obtaining Consent

When the researcher met with the caregivers any further questions about the project were answered and a consent form (Appendix D) was filled in and signed by the caregiver.

One caregiver was most willing to participate but due to his caregiving situation did not feel able to meet with the researcher. A permission form was delivered to him and after being signed and returned to the researcher the interview was conducted on the phone.

All caregivers were given the researcher's contact information in case they wished to change or withdraw the information they had provided.

Interview Outline (Appendix E)

The researcher conducted all interviews following the outline prepared by the Management Group. Many caregivers discussed additional matters not covered by the Outline. They and not the researcher initiated those discussions.

Recording Data

The researcher recorded information in writing while the interviews were being conducted. Afterwards the data was categorized according to the outline provided by the Management Group.

Categorization of Caregivers Interviewed

The vast majority of the unpaid caregivers who were interviewed are themselves seniors (15 aged 50 to 59; 19 aged 60 to 69; and 18 aged 70+).

More than two thirds of the caregivers are female.

They are caring for family members who are older than themselves (59 aged 70+).

The usual pattern is for a son or daughter to be caring for a parent or parent-in-law (39 cases).

The next most common pattern is for a spouse to be caring for a partner (20 cases).

Most of the full time year around caregiving had been for more than 2 years.

The vast majority of caregivers live in their own homes (57) and those they care for live with them (38) or within 25 kilometers (19).

Additional information can be found in the details and tables in Appendix G. Supplementary Information

SURVEY DATA

In most cases the interview followed the outline prepared by the Management Group. (Appendix E) In two instances the focus of the leading question was rephrased. The first question, “Are you able to add caregiving hours to your other responsibilities?” was modified to ask if it had been difficult to add caregiving hours to their other responsibilities. The other change was to the question, “Are you able to accept offers of help from others?” which was changed to “has there been any offers of help from others?”

We shall use “24/7” to describe the unpaid caregiver who lives in the same home with the care receiver. Such a caregiver is effectively never off duty. For 38 of the 64 caregivers interviewed this was their situation. They lived with, or had lived with, the care receiver.

It was expected that the caregivers would determine the scope of the interviews. The intent of the Outline was to cover all aspects of the caregiver’s situation. The interviewer wrote down what she heard and when required reordered the data according to the Interview Outline. Those reordered notes are included as Appendix H. Survey Data from Interviews. The following are abstracts from the data.

1. The caregiver’s assessment of their capacity to provide care.

Most caregivers interviewed said that the amount of care they provide(d) began with a smaller amount and tended to increase gradually over a period of time.

All parents caring for children with lifelong disabilities had chosen to look after their children rather than have them institutionalized. All are concerned about the time when they are no longer able to provide care. They are making plans for their children’s future care.

For the 24/7 caregiver, most outside activities have had to be given up except in one instance where the care receiver has sufficient income to cover the cost of having professional care providers in the home at all times.

Many expressed great concern and worry about the wellbeing of care receivers still living alone or living with someone not able to adequately care for them due to their own age or infirmity.

In general, caregivers who knew where to turn to get the professional help they needed were able to get it. Those who were not aware and were inclined to be timid about asking for assistance tended to miss out.

Some expressed concerns about; the services of Home Care, information from doctors or other professionals, and looking after their care receivers when they were discharged from hospital.

In the majority of cases the overall planning and providing for their loved one’s care fell to the caregiver, and not the professionals.

Offers of assistance from family and friends tended to be more frequent during times of crisis or near Christmas but fell away when the caregiving situation was prolonged.

When personal care was involved, caregivers preferred respite from someone of the same gender as the care receiver.

Most caregivers said they were satisfied they were able to find out what they needed to know. Some caregivers were able to identify what they needed to know. But not that there was far more information available than the limited amount they were able to glean.

All caregivers were handling the extra costs of caregiving, including the “hidden” costs, but some had more difficulty than others depending upon their income and ongoing expenses. In some situations it meant that there was no money for anything beyond the bare necessities.

2. The caregiver looking after his/herself

All caregivers providing full-time care (24/7) lacked sufficient respite time. Most did not wish to ask family or friends to give them a break in case they needed to call on them in a crisis. In situations where another family member or friend offered to take over at a specific time, the caregiver was inclined to accept the offer.

There was a recognized need for a “Vacation”. Having some “time away”, as in days rather than hours, was the dream of many.

Some caregivers felt that the care receiver made it very difficult for them to leave even when respite breaks were made possible. Their care receivers felt they were capable of caring for themselves and therefore resented having someone come to be with them.

Most receiving care had no concept of how much was being provided for them and therefore little grasp of why the caregiver would need a break.

Those providing care to someone not living in their home had more freedom to do other things.

Over half of the caregivers felt they did not receive the emotional support they needed from their community or church family with some being uncertain of what emotional support would feel like.

Those who are still active in church groups have tended to feel far more emotional support than those who are not.

Many expressed that their needs were not understood, whether by their minister or priest or by visitors from the church. Several expressed that this type of visit was draining since they felt they had to entertain the visitor.

The majority of caregivers reported they did not receive the emotional support they needed from their families. Some had no family members living close enough to spend time with them, or had no family members physically or emotionally well enough to meet their emotional needs.

All caregivers agreed that they noticed some or all of the signs of stress and exhaustion as a result of caregiving, e.g. sleeping poorly, crying frequently, irritable, feeling overwhelmed, feelings of resentment, inadequacy, etc.

Most 24/7 caregivers said they recognized the need for more exercise but they were not able to leave the care receiver unsupervised.

Only one caregiver took a compassionate leave from work and then returned to their employment after the death of his loved one.

About half of the caregivers interviewed were not aware of the caregiver tax credit on their income.

3. Caregivers Assessing their Spiritual Needs

Although almost all caregivers interviewed had not done a formal assessment of themselves, all had previously given thought to their desire and ability to provide care.

There was a definite tendency for the males in the family to feel that caregiving was something that women would do although interviews were conducted with men who had become caregivers to their loved ones and felt it was their responsibility.

None of the caregivers interviewed questioned their overall ability to provide care although a few did voice questions about how long they could continue to give the care necessary, especially if the needs increased. For some caregivers there was a natural concern expressed about what would happen if they were no longer physically or mentally capable of providing care.

Many suggested that the amount of care given had increased gradually and that they were surprised at the huge amount of time and energy it now took.

Refer to detailed listings in Appendix H. SURVEY DATA FROM INTERVIEWS

- 3.b. ways of dealing with feelings of guilt or inadequacy;
- 3.c. finding help in increasing and strengthening spiritual awareness;
- 3.d. provide for the spiritual well-being of the person being cared for;
- and 3. e. how churches can help them in their role as caregivers.

FINDINGS

A. RESPITE

Consistently the top desire expressed by almost all caregivers interviewed was for more respite care. Recognizing the limitations of what is available from Home Care and that caregivers or care receivers did not have the financial resources necessary to hire other professional care providers, offers from trusted and capable volunteers would be welcomed. Many stated that someone who would befriend the care receiver and take a genuine interest in him/her rather than just coming as a “sitter” would be a wonderful gift. This would require that the same one or two people came consistently.

B. CONTACT FOR INFORMATION

The majority of caregivers expressed their desire to have someone in the area they could call or visit about any caregiving needs. These ranged from what to do, where to get the help or equipment needed and what resources are available in the area, to needing an understanding but objective ear. It was felt that knowing someone was there when there was a need would bring a great sense of security and reduce some of the stress many were experiencing. Many caregivers voiced their desire to have an up-to-date directory of all available local, provincial and national resources and services. Almost as many felt that it would be next to impossible to keep such a directory continually updated and felt that having a person with whom they could discuss things would be more beneficial. However, if no such person were hired they felt a directory, which separated local resources and services from provincial and national ones, would be of great benefit.

C. VISITATION

Regular visitation in the form of good pastoral care was high on the list of expressed needs. Caregivers indicated their desire for regular visits from a sensitive and understanding visitor in addition to visits from their minister or priest. Many caregivers first focused on the need for pastoral care for the care receiver but also shared their own need for visits. It was often voiced that having the same person coming consistently would be of the greatest benefit. All said they were grateful for calls from lay visitors as long as they did not replace visits from the clergy.

D. SERVICES

Assistance in the form of providing transportation for caregiver, care receiver or both was high on the list of things that would help. Some care receivers have numerous medical appointments with several receiving regular treatments or therapy. A few caregivers do not own or drive vehicles but even those who do find the extra trips necessary very tiring. When care receivers are well enough to attend church or groups of interest, someone to take them and/or bring them home would be greatly appreciated by their caregivers.

RECOMMENDATIONS

Taking into consideration the very real needs of our caregivers and their very reasonable wishes, the following major recommendations are made:

- that a co-ordinator/resource person be hired to be available to all caregivers living in the Wolfville area or affiliated with any churches belonging to the Wolfville Area Interchurch Council, to volunteers, and who would work with all churches who are part of the Wolfville Area Interchurch Council
- that volunteers be found, carefully screened and well trained to help caregivers and care receivers in accordance with the talents and abilities of the volunteer and the needs expressed by the caregivers, and that they receive regular ongoing support and opportunities for additional training or education pertaining to caregiving issues
- that caregivers and those for whom they care receive improved pastoral care
- that a website for caregivers in the target area be developed listing all local resources and enabling a caregiver network of support to be established
- that there be affirmation and recognition of caregivers in our churches and communities initiated by our churches
- that workshops be offered for caregivers according to the interests and needs of our caregivers
- that a committee comprised of those interested in furthering the efforts made to assist our caregivers be established; some past and present caregivers interviewed expressed their desire to be a member of such a group
- that every effort be made to raise local public awareness and understanding about caregivers and their challenges

APPENDICES

- A. Time for Caregivers Health Project Proposal 2004.03.31
- B. Time for Caregivers A Request for Endorsement 2004.05.10
- C. Guidelines for the Researcher 2004.08.13
- D. Consent Form 2004.08.13
- E. Interview Outline 2004.08.13
- F. Job Description for Researcher 2004.08.13
- G. Supplementary Information on Those Interviewed
- H. Survey Data from Interviews

APPENDIX A

TIME FOR CAREGIVERS HEALTH PROJECT PROPOSAL 2004.03.31

A ministry of the churches in Wolfville to those providing regular assistance to another individual in need of care, as part of a team of formal and informal caregivers. The Wolfville Baptist Church is petitioning the Foundation on behalf of the other churches in the Wolfville Area InterChurch Council for a ministry to the general population of Wolfville and Area.

Our primary focus is on the informal caregiver who in a volunteer capacity provides care for a loved one. It is our understanding that unpaid caregivers themselves are at risk while caregiving for another, and require understanding, encouragement and companionship. It will enhance their quality of life and extend their independent living.

Research of the Genuine Progress Index organization in Kings County has data that supports that understanding. And there are more than 5000 in Kings County that fall into that category. This is one item not included in the Romanow Commission report "Shape the Future of Health Care". The Canadian Association of Retired Persons (CARP) participates in a coalition which seeks to bring the needs of the unpaid caregiver to public attention.

Objectives for the next twelve months:

1. In the first instance to identify informal caregivers in the community, and carry out an interview with them to discover and document their needs. The scope of the interview would be holistic, and the needs recorded would include those physical, emotional and spiritual.
2. In an interdisciplinary approach, to partner the VON, the EKM Community Health Centre, the Mental Health department of the Annapolis Valley Health Authority, Community Links, and the Family Caregivers Association of Nova Scotia, in providing resources to caregivers in our community.
3. To compile a bank of resources in print and on video cassette, and make those available through the Health Quest library at the Health Centre.
4. To propose to our partners and the ecumenical community, specific service programmes and personnel support for informal caregivers in our midst, matching their physical, emotional and spiritual needs.

Expected outcomes:

1. By providing support to the unpaid caregivers in their current circumstances, in many instances this will foster independent living, and delay the institutionalization of the care receiver.
2. By the systematic interaction of the InterChurch group and the caregivers in the community, there will be a significant enhancement of the quality of life of both the caregiver and care receiver.
3. Raise the awareness in the general population of the challenges facing caregivers and what an essential service they provide.

Action Plan:

To establish an InterChurch management group and appoint a part-time Program Coordinator. The Coordinator will work with our partners (VON, Health Centre, etc) and will begin interviews with caregivers identified by churches and other service organizations. There will be a provisional phone number and website as a contact point for information and assistance.

In March the Wolfville Baptist Church group did contact more than 50 caregivers in the area and discovered almost as many needs as their were respondents:

- personal contacts (keeping them involved in community life),
- respite (both regular and unscheduled visits to provide refreshing breaks),
- transportation (incidental sightseeing, visits to worship services, banks, shops and medical appointments),
- extra support at times of crisis or transition (when the caregiver feels overwhelmed),
- and generally all sorts of information on future options for both caregiver and person cared for.

Spiritual therapy would include providing the means to deal with dealing with feelings of guilt, anger, inadequacy, grieving, death & dying, and anxiety about that day when they are not able to cope. The challenge of matching all those needs is daunting. There is a lack of awareness of the trials and stresses of the caregivers in the community.

In the first year the management group will fashion an appropriate design for the program which can be sustained by the churches on their own. Previously the Wolfville Area InterChurch Council established InterChurch Housing, and Meals on Wheels, which are sustaining. There is confidence the same can happen for "Time for Caregivers".

Original Task Group:

Jennifer Longley, volunteer coordinator for Friends In Bereavement

(<http://ace.acadiau.ca/grief/friends.html>), former full-time caregiver, and member of the Board of Directors of the Family Caregiving Association of Nova Scotia.

Heather Taylor, Interim Associate Minister of the Wolfville United Baptist Church, with special interests in elder care.

Howard Taylor, retired chaplain/counsellor with Mental Health Services, instructor in Clinical Pastoral Education.

Roger Cann, past chair of Community Health Board and former member of the EKM Health Centre Council.

APPENDIX B

TIME FOR CAREGIVERS – A REQUEST FOR ENDORSEMENT (2004.05.10)

Member parishes and congregations of the Wolfville Area Inter-Church Council are requested to endorse the “Time for Caregivers” project. “Time for Caregivers” focuses on a ministry to those providing regular assistance to another individual in need of care, as part of a team of formal and informal caregivers. The Wolfville Baptist Church petitioned the Eastern Kings Memorial Health Foundation on behalf of the other members the Wolfville Area Inter-Church Council for financial assistance for the project to reach the total community in Wolfville and Area.

The original request for funding was for \$12,000.00 for a twelve month survey, study and design project. The Foundation granted \$6,000.00 to carry out the following:

1. Interview informal caregivers in the community, and document their needs; physical, emotional and spiritual.
2. Work with partners such as HomeCare, the VON, the EKM Community Health Centre, the Mental Health Department of the Annapolis Valley Health Authority, Community Links, and the Family Caregivers Association of Nova Scotia, to provide resources to caregivers in our community.
3. Propose to our partners and the ecumenical community at large, specific service programmes and personnel support for informal caregivers in our midst, matching their physical, emotional and spiritual needs.

By providing support to the unpaid caregivers in their current circumstances, in many instances this will foster independent living, and delay the institutionalization of the care receiver. Through the interaction of the Inter-Church group with the caregivers in the community, it is hoped that there would be a significant enhancement of the quality of life of both the caregiver and care receiver. A side benefit will be to raise the awareness in the general population of the challenges facing caregivers and what an essential service they provide.

An essential component of this ministry is what may be termed “Spiritual Therapy”, that is providing the means to deal with feelings of guilt, anger, inadequacy, in times of grieving, confronting death & dying, and anxiety about that day when they are not able to cope.

Beginning in May 2004, members of the Wolfville Area Inter-Church Council are requested to give an endorsement to this ministry, and for each to name a single individual to a management group. This group will establish its own pattern of administration, and appoint a part time coordinator. The coordinator could begin work in September.

Rev Dr. Roger Cann

2004.05.10

1032 Club Crescent New Minas NS B4N 4Z5
phone 681-2448 email <roger.cann@ns.sympatico.ca>

APPENDIX C

GUIDELINES FOR THE RESEARCHER

SURVEY OF UNPAID CAREGIVERS 2004.08.13

1. The researcher must not take on the role of counsellor or intervene in any way into the caregiving relationship. This is important as the researcher is in a paid position and incurs liability for the ecumenical management group.
2. The researcher should guard against any negative impact of the interview, that is, causing anxiety due to the probing of feelings.
3. Depending on the context of the interview the researcher may supply a document for self-assessment of their pastoral needs.
4. It would be helpful to have a prepared check-off list for the interviewee of many of the items to be considered in a family caregiving situation.
5. The interviewee will have difficulty in comprehending exactly what the researcher is after (cognitive) and there will also be a common reticence to reveal personal feelings to a stranger. There will be a tendency for the interviewee to respond with what is thought to be an answer that the researcher is looking for, rather than actual feelings. The results of the survey would be understood as being what has filtered through those three screens.
6. The researcher should be sensitive of the feelings of the interviewee, and humble enough to refer that person, or family unit, for follow up by other qualified personnel. The Valley Pastoral Counselling Association has/will have a pamphlet dealing with referrals.

APPENDIX D

SURVEY CONSENT FORM

I am Jennifer Longley, a researcher from the Wolfville and Area InterChurch Council. I would like to hear about your experiences looking after a member of your household, or a family member or friend living elsewhere for whom you have taken some responsibility. I would like to learn what you find helpful, and also what you find not so helpful, and what help you wish were available to you.

We appreciate your willingness to allow me to interview you. If this time is now not the best for you, please don't hesitate to tell me and we can reschedule a visit. I do understand that the demands on a caregiver's time and energy are almost never-ending and that many unexpected situations can make it necessary to alter plans. If you'd like to have a friend sit in on the interview they would be most welcome. SHALL WE PROCEED?

After we start the interview, should you find that you do not wish to continue, please tell me. If I ask a question or questions you prefer not to answer, that is perfectly OK with me so please just indicate that. If you later decide you don't want me to use the information you gave me you need only contact me to let me know.

The information I get from you will be used in planning a ministry of the Wolfville churches to support unpaid caregivers but your name will not be used. I will respect your openness by keeping the source of the information confidential. I will be keeping my notes and survey questionnaires in a safe place. After I have produced a report without identifying specific people, I will be destroying those notes. DO YOU HAVE ANY QUESTIONS OR COMMENTS?

If there is anything you would like to discuss with me in the future, I can be reached at 681-8239 (Jennifer Longley). Please leave a message if I'm not there when you call and I'll get back to you..

Your name: _____ Address: _____

Phone number: _____ Email: _____

Signature: _____ Today's Date: _____

THANK YOU FOR YOUR PARTICIPATION!!

WE PRAY THAT THROUGH WHAT YOU HAVE SHARED OUR CONGREGATIONS WILL
BECOME BETTER AWARE OF THE NEEDS OF OUR MANY CAREGIVERS AND LEARN
HOW BEST WE CAN HELP!

APPENDIX E

INTERVIEW OUTLINE: SURVEY OF UNPAID CAREGIVERS

Basic information:

Family name:

Given name: known as:

date of birth (if permitted)

Postal address:

Civic address:

Phone number:

email address:

Household information:

Own home/rented:

Others in home: Pets:

Interview context:

Time of day: Location:

Those present:

a. Can you arrange for respite (time off) from caregiving? Do you know of the availability of such services in the community? Within the family?

b. Can you get the emotional support you need (community, church, other family members)?

c. Can you recognize signs of stress and exhaustion, e.g. sleeping poorly, crying frequently, irritable, feeling overwhelmed? feelings of resentment, inadequacy?

d. Can you maintain your health through exercise, diet and regular medical check-ups?

e. Are you eligible for compassionate leave through Employment Insurance 1-800-622-6232? (Could provide an information sheet)

f. Are you eligible for caregiver tax credit 1-800-959-8281? (Could provide an information sheet)

I. Dealing with the person's self-assessment as to their capacity to provide care

a. Are you able to add caregiving hours to your other responsibilities? To what limit?

b. Are you able to get help for planning and providing care from professional care providers? From family members?

c. Are you able to accept offers of help from others? (May be important to discovered the gender of those "others". Preference for male? Or female?)

d. Are you able to identify and get the knowledge you need to provide care, e.g. safe lifting, bathing, understanding dementia?

e. Can you handle the additional costs involved?

II. Looking after yourself (worthwhile to have a detailed check-off list of items to be considered)

III.

III. Assess your Pastoral Needs (There will be a need to restate the questions in terms common to the caregiver. It may facilitate a response by sharing a list of potential services which a parish or congregation might provide))

a. Are you able on your own to evaluate your desire and ability to provide care? Is this a "compulsory" charge? Are you an "accidental" caregiver?

b. What are some of the ways you deal with feelings of guilt or inadequacy for the caregiving task?

c. What are some of the ways you find helpful in increasing and strengthening your spiritual awareness? (Facilitating your sense of wholeness, sustaining a sense of wholeness in living, feeling God's presence)

d. What do you aspire to provide for the person your are caring for in terms of spiritual well-being? How will you do that?

APPENDIX F

TIME FOR CAREGIVERS 2004.08.13
Staff Position: RESEARCHER Job Description

Major tasks:

1. Carry out survey of unpaid or family caregivers in Wolfville and Area
2. From the survey, identify the needs of caregivers in our area
3. Consult care providers and potential partner organizations and agencies on needs and resources
4. Protect confidentiality of respondents, and compile data from surveys and consultations
5. Facilitate working sessions with ecumenical management group on strategies
6. Negotiate with partner organizations and agencies and initiatives to be taken

Accountable to the ecumenical project management group, through the convenor, who would give initial appointment, set priorities, specify directions and provide supervision. The researcher would report bi-weekly (fortnightly) in detail as to tasks completed.

Terms of employment:

Beginning in September, or October 2004, at the latest, on average two days a week (16 hours), focussed on the major tasks. The appointment would be for four months. Future work will depend on new funding. Pay and allowances according to qualifications starting at \$12.00 an hour, with 4% of gross pay in lieu of holidays/vacation.

The management group will give public notice (cable, newspapers, Internet) of the survey and solicit participation.

The management group will provide parish and congregational lists, and assist in carrying out the detailed interviews where necessary.

QUALIFICATIONS:

1. Church/parish member concerned about caregiving
2. Demonstrated pastoral and/or counselling skills
3. Computer literate
4. Available for part-time position
5. Has own transportation

APPENDIX G

SUPPLEMENTARY INFORMATION OF THOSE INTERVIEWED

- Ages of Caregivers: Under 30 – 0; 30-39 – 2; 40-49 – 5; 50-59 – 15
60-69 – 19; 70-79 – 11; 80-89 – 5; 90+ - 2
- Ages of Former Caregivers when giving care: Under 30 – 1; 30-39 – 1
40-49- 0; 50-59- 2 (a couple); 60-69- 2 (a couple)
70-79- 0; 80-89- 1; 90+ - 0

Notes: One couple (above) are currently caregivers to an adult son and also were interviewed as past caregivers to the husband's mother.

Some caregivers interviewed were caregivers to those who have died and are now caregivers to other loved ones. Although information was given about past experiences, statistics reflect their current situation.

Special situation:

One family of 3 comprised of mother in her 70's and a son and daughter in their 40's. All are caregivers to one another and do things for one another although neither the mother nor the daughter could manage without the son; he would be able to live independently but definitely benefits from the care of his mother and sister. This family is not included in the numbers of any categories of either caregivers or care receivers since members fall into several categories. Their input into other questions will be included later in the report.

- Ages of Care Receivers at the time of the interview:
Under 9 – 0; 10-19 – 1; 20-29 – 1; 30-39 – 0; 40-49- 2
50-59- 4; 60-69- 1; 70-79- 17; 80-89- 31; 90-99- 10; 100 - 1

Note: Of these, 2 have died since their caregivers were interviewed.

- Ages of Care Receivers (already deceased at time of the interview) when they died:
Under 29 – 0; 30-39 – 1; 40-49 – 0; 50-59 – 0; 60-69 - 0
70-79 – 1; 80-89 – 3; 90+ - 0

Note; 10 Caregivers are providing care to more than one person (2 in each instance)

- Gender of Caregivers, both past and present:
Female – 47
Male - 17
- Relationship of Caregiver to all Care Receivers (living or now deceased):
Wife caring for husband – 11 Husband caring for wife – 9
Daughter caring for parent(s) – 27 Son caring for parent(s) – 7
Son-in-law or daughter-in-law caring for parent(s)-in-law - 5
Parent(s) caring for child – 3 Sibling caring for sibling – 2

Cousin caring for cousin – 1

Friend caring for friend(s) – 1

Note; some of these caregivers are/were, caring for more than one person.

- Length of time providing care:

24/7 caregivers had been providing care for 2 months to 22 years; most had been caregivers for over 2 years

Caregivers not providing full-time care had been doing so for 2 months up to 26 years

Most caregivers were unable to identify exactly when the care given became more than what one does to help another

- Caregivers interviewed live in Wolfville, Lower Wolfville, Greenwich, New Minas, Port Williams, Greenfield, Melanson, Grand Pre, Avonport, Black River Lake, Canaan, Kentville and Cambridge, NS. Of these, one is temporarily living with the care receiver in another community. It will not be identified in order to assure anonymity.
- Of those caregivers presently giving care, 38 live or were living with the care receivers. 19 live(d) within 20 miles of the care receiver and 6 caregivers are providing ongoing and regular long-distance care. In these instances care receivers live in Western NS, Halifax (2), Cape Breton, on the South Shore of NS and in Ontario.
- 5 caregivers are renting their accommodations and 59 live in their own homes. One caregiver has currently left her own home to provide care in the care receiver's home. In a few instances it was mentioned that two households had been combined to make care possible with either the caregiver or care receiver giving up their own accommodations to move in with the other.
- 5 caregivers currently providing care live alone. In 4 instances, the care receiver is now residing in a long term care facility and in 1 instance the care receiver is still living on their own with help.
- 1 former caregiver lives alone due to the death of her spouse.
- 37 caregivers live with one other person and 21 caregivers had from 2-6 others living with them.
- Of the 65 caregiver interviews with 64 caregivers, 23 caregivers have pets. Of those who do not have a pet, some expressed regret that pets were not allowed where they live. Several other caregivers said they could not possibly care for anything else.
- Of the 65 interviews, 55 were conducted at the home of the caregiver(s), 3 were conducted at the caregiver's place of employment, 2 were conducted in coffee shops, 1

was conducted in a church and information was given over the phone by 4 caregivers. The researcher conducted 65 interviews although two were with the same caregivers but with regard to different care recipients.

- Three interviews were conducted on a weekend, one on a weekday evening and 61 during the day on a weekday. One caregiver was not home when the researcher went to the home so the researcher had to return a second time.

Of the 64 daytime interviews, 27 were conducted in the morning and 37 in the afternoon.

Three other interviews had been booked but cancelled due to:

- nobody being home
- caregiver not available due to the care receiver's hospitalization
- the death of a care receiver just prior to the scheduled interview

Two additional caregivers opted to send their information by e-mail but neither followed through.

Interviews were from 50 min. to 2.5 hours in duration with approximately 75% taking around 90 min.

24 caregivers had someone else present during all or part of the interview, and in 16 instances it was the care receiver.

- Care Receivers required care due to the following conditions:

Stroke	Heart condition	Kidney disease
Cancer	Alzheimer's Disease	Cerebral Palsy
Dementia	Memory loss	Blindness
Deafness	Diabetes	Neuropathy
Post Polio Syndrome	Multiple Sclerosis	Down's Syndrome
Parkinson's Disease	Short-term recovery following car accident	
Aneurysm casing brain damage	Loss of mobility	Frail elderly

In many instances care receivers had several health problems.

Many caregivers mentioned physical or emotional challenges of their own and that they were being treated for depression.

APPENDIX H

SURVEY DATA FROM INTERVIEWS

Interview Questions:

I. Dealing with the caregiver's assessment as to their capacity to provide care

a) Are you able to add caregiving hours to your other responsibilities?

With few exceptions caregivers felt this a “ridiculous” question to be asked, and indicated that “you just do it” or “you do what you have to”.

Since all interviewed are or were caregivers, they were already adding caregiving hours to their other responsibilities. The question was then modified to ask if it had been difficult to add caregiving hours to their other responsibilities. To this wording caregivers gave varying answers which indicated that the difficulty was in proportion to the kind and amount of care needed in addition to what other responsibilities they already had.

The second part of the question asked “To what limit?”

This question elicited varying responses according to the amount of care they were providing and the amount of help available to them.

The greatest percentage of caregivers interviewed said that the amount of care they provide(d) began with a smaller amount and tended to increase gradually over a period of time. All parents who have cared for children with lifelong disabilities chose to look after their children rather than having them institutionalized. It has meant many personal sacrifices and yet they remain committed to providing the care they do. All look ahead to the time when they are no longer able to do so and are making plans for their children's care.

When a care situation arose suddenly it was difficult to adapt to it quickly. Caregivers working outside the home said that there are definitely limits on their time and energy but some expressed their gratitude for understanding employers and/or co-workers who have made it possible for more flexible work hours and sometimes extra time off. The few caregivers who still have children at home try not to neglect them while juggling caregiving responsibilities but admit there are times they are not successful. In most instances the spouses of caregivers have been somewhat supportive and helpful although in a few situations there has been resentment.

For the 24/7 caregiver, most outside activities have had to be given up except in one instance where the care receiver has sufficient income to cover the cost of having professional care providers in the home at all times. For those providing long distance care, their daily lifestyle is not as affected when they are at home but their time and energies are totally given to the care receiver when they go to be with them and attend to their needs. Caregivers providing care to a relative or friend living nearby have a mixture of some freedom to continue regular activities and yet more time needed to look after their own homes as well as overseeing or providing the care to those needing it. Many expressed great concern and worry about the wellbeing of care receivers still living alone or living with someone not able to adequately care for them due to their own age or infirmity.

b) Are you able to get help for planning and providing care from professional care providers?

Since most caregivers could not afford to hire professional or private care providers they had to rely upon the services of Home Care, or a V.O.N. nurse when there was a situation warranting some nursing care at home. Most were appreciative of the services they had received but felt the need for more respite care. Due to the number of clients receiving their services, care receivers had to be worked into the care provider's schedule, which sometimes worked very poorly. Several caregivers chose to bathe the care receivers themselves rather than making them wait for the professional care provider to arrive later in the day. Waiting was upsetting to both caregivers and care receivers and resulted in poor days. A few caregivers had not accessed the care available due to fears about how much it might cost them. While some caregivers had been made aware of other possible help through Veterans Affairs or organizations, there was not consistency in the information that was provided to some and not to others. In general, caregivers who knew where to turn to get the help they needed were able to get some, while those who were not aware and were inclined to be timid about asking tended to miss out on some avenues of assistance. One caregiver said she had to learn from non-professionals about how to provide care.

At least 6 caregivers mentioned their anger and frustration over not being able to get the information they needed from the doctor of the care recipient due to confidentiality practices. The caregivers felt there were serious concerns about their family member but without input and direction from the doctor it was extremely difficult to know where else to find out what their condition warranted in the way of care needed. Several caregivers noted that their care receivers did not want them speaking to their doctors. One caregiver felt that specialists and family doctors had poor communication resulting in things being overlooked and information not shared.

Additional comments expressed frustration at the outdated list of private care providers which was given to some caregivers prior to their family member being discharged from the hospital and requiring extra care. Those on the list were not available, could not be reached due to changed telephone numbers or no longer did this kind of work, which added to the anxiety already felt by the caregivers.

One caregiver was unable to hire an RN to be with the palliative care receiver who needed pain medication administered during the night, even though insurance provided ample coverage to pay a nurse. As a result the caregiver had to give these injections herself which meant her sleep was interrupted each night.

Are you able to get help for planning and providing care from family members?

In a minority of situations family members were helpful by working with the caregiver to find out what was needed and available or by sharing some of the care providing themselves. Some were supportive but did nothing to help arrange for the necessary care. In many situations other family members lived at too great a distance

away to be able to give much help. In the majority of cases planning and providing for their loved one's care fell to the caregiver.

c) Are you able to accept offers of help from others?

Due to negative reactions to this question, the researcher soon began asking first if there had been any offers of help from others. Approximately half of the caregivers interviewed said there had been no offers to help them; most offers were to help the care receiver by visiting infrequently or in small ways like sending a card or small gift for special occasions. While appreciated, these expressions of care usually did not help the caregiver unless the visit was from someone familiar who could fit into the situations rather than just being another person to entertain. Offers tended to be more frequent during times of crisis or near Christmas but fell away when the caregiving situation was prolonged.

When asked about gender preference if or when someone offered to help, most said it would depend upon the type of help being offered. Most had no preference although if it was to sit with someone bedridden or provide respite care, which might involve some personal care, caregivers preferred someone of the same gender if the care receiver was female. The spouse of an Alzheimer's patient said her husband would be very confused if a female came to sit with him or offered to take him for a drive if she wasn't present too. Of even more concern was that the person be trusted and known to the caregiver or to someone else they knew and trusted. It was not important to anyone asked if the helper was from the same church as the caregiver or the care receiver.

d) Are you able to identify and get the knowledge you need to provide care, e.g. safe lifting, bathing, understanding dementia?

Most caregivers said they were able to find out what they needed to. One caregiver said she was never able to get adequate information about pain management. Another caregiver expressed extreme frustration that the nursing staff at the hospital would never give her a full explanation about what medications her husband was being given and his doctor always came around long before visiting hours. Two members of one family sought information from the Cancer Society about where to obtain the necessary medical equipment and each were told they didn't provide that information and no suggestions were made. If one were to assess each situation it might reveal that not all caregivers were able to identify what they needed to know or that there was far more information available than the limited amount they had.

e) e.Can you handle the additional costs involved?

It first had to be determined if there were indeed additional costs involved to the caregiver and in almost all instances there were despite their initial answers. Once more thought was given to the question, the caregivers began realizing that there were many "hidden" costs such as extra gas needed for driving the care receiver to medical appointments or for the caregiver to go the home or institution where the care recipient resided, to run errands, to pick up or return medical equipment, to keep the home warmer than usual, for extra long distance calls made, parking costs for medical appointments or hospital visits, etc. Caregivers were far more aware of the noticed costs of needing to buy special food, incontinence supplies, medication not

covered by Pharmacare or an insurance plan, hiring a “sitter” or paying for respite care elsewhere on rare occasions, equipment needed or home modifications etc. Most care receivers had sufficient income to cover these costs but often not to cover the “hidden” costs to the caregiver. Some older care receivers or those with some dementia had no awareness of the actual cost of things or that the caregiver was incurring extra expenses on their behalf.

A small percentage of caregivers were affected by the loss of a second income when the care receiver was no longer able to work. Those whose spouses were now residing in a long-term care facility were also greatly affected by the reduction in household income and the high costs of care.

One caregiver could not afford a very necessary addition to the home, which means the care receiver sleeps in a hospital bed in the livingroom and is not able to access the bathroom which is on another floor; the care receiver is no longer physically able to use the stair lift. If the care receiver used her former room upstairs, she would be isolated from the rest of the household most of the time and would not be able to be taken outside. The caregiver has cared for the care receiver for 22 years and has explored all avenues of possible financial assistance.

Therefore, all caregivers were handling the extra costs but some with more difficulty than others depending upon their income and ongoing expenses. In some situations it meant that there was no money for anything beyond the bare necessities.

II. Looking after yourself

a) Can you arrange for respite (time off) from caregiving?

In almost all instances caregivers felt that they could arrange for the care of the care receiver in an emergency situation. Two caregivers however did have serious concerns about what plan could be put in place for their loved one should something unforeseen arise.

All caregivers offering full-time care did not have enough respite care and most did not wish to ask family or friends to give them a break in case they needed to call on them in a crisis. In situations where another family member or friend offered to take over at a specific time, the caregiver was far more inclined to accept the offer.

Many caregivers had no other family in the area and in some cases their family lived in other provinces. Some had family in the area or at a distance who were unable or unwilling to help. Those receiving Home Care services were only allowed a minimal amount of respite time weekly and oftentimes the caregiver had to use it to take care of necessities such as buying groceries, attending to business, running errands, purchasing medications or other medical supplies, and keeping their own medical appointments. Consequently there was little or no rest or relaxation involved during their “time off”. Oftentimes if the Home Care worker providing respite care was unable to come there was no back-up worker available and therefore no respite care was given in those instances. Many caregivers also voiced that they had little energy or insufficient financial resources to go and do some of the things they might once have enjoyed doing even if they could have more hours of respite time. Having some

“time away”, as in days rather than hours, was the dream of many. They felt it would make them much better caregivers and bring things back into perspective if they could have what felt like a “real” break from their caregiving duties. None expressed the desire to stop being caregivers. Three caregivers did not have vehicles making respite breaks even more limiting.

One caregiver interviewed knew she could no longer cope with the increasing needs of the care receiver and was expecting his placement in a long-term care facility to be within the very near future. She did feel she could manage until the placement was arranged. Less than two months after the interview that did occur. She continues to be his caregiver but now has many others providing his care. Another caregiver felt that there would not be anyone willing to give him respite breaks due to the needs of his loved one, living at home, who has fairly advanced Alzheimer’s disease.

Some caregivers expressed that the care receiver made it very difficult for them to leave even when respite breaks were made possible. Their care receivers felt capable of caring for themselves and therefore resented having someone come to be with them. They were not capable and to leave them alone would be unsafe and negligent. When workers or others came to give these caregiver a break, their care receivers either exhibited difficult behaviour or took it out on the caregiver later. Most receiving care had no concept of how much was been given to them and therefore little grasp of why the caregiver would need a break.

Caregivers to those having home kidney dialysis were never able to have a break any longer than a few hours due to the necessity of being present to oversee and if needed help with the dialysis process. A caregiver whose loved one receives dialysis in Berwick three times a week always stayed long enough to be sure the treatment was going to go smoothly and was always “on guard” at all other times due to what might, and often has, gone wrong both during and between treatments.

Those providing care to someone not living in their home had more freedom to do other things in some ways but were at a disadvantage in others. Their time and effort was seldom fully recognized by others so their need for a break from caregiving was usually overlooked. In addition most still had a lot of the ongoing stress and fatigue which other caregivers experienced.

One caregiver pays a private care provider to visit the care receiver in his long-term care facility and take him outside daily when possible. The family caregiver is then able to enjoy more peace of mind and is less tired. She visits the care receiver almost daily but now experiences less stress knowing her loved one is receiving extra visits from the private care provider.

b) Can you get the emotional support you need from your community, church and other family members?

There are no clearly defined boundaries of community and church in the minds of most interviewed; the people in their church are also the people in their community.

Over half of the caregivers felt they did not receive the emotional support they needed from their community or church family with some being uncertain of what emotional support would feel like. Others noted that they had not made an effort to let the community know about their emotional needs and therefore were not terribly surprised that they weren't being met. Several caregivers expressed that they were "private people" and therefore didn't talk about their situations elsewhere. One caregiver stated that his place of employment and its other employees had long been his "community" and that since retiring and needing to forego most outside activities due to his caregiving responsibilities, he now felt forgotten or invisible in the eyes of both the work and civic community.

Those who are still active in church groups have tended to feel far more emotional support than those who are not. However, if they have not been able to continue to be actively involved, the support has dwindled or even stopped as time has gone on. Those who attended church but were not involved in other church activities often felt their absence was not even noticed, or if still attending that their situation was not known about or not understood if it was known. Although occasional cards, flowers, baking or fruit baskets, usually sent to the care receiver, were appreciated, they did not meet the caregiver's need for personal caring and support.

Overall the minority of caregivers who had sought help from their minister or priest had not had their needs met and would be unlikely to request help from the same person again. Those who had specifically requested a visit from the minister or priest had usually received one but when not requested, most had received few visits and several had never had any. Many expressed that their needs were not understood, whether by the minister or priest or by visitors from the church. Several expressed that this type of visit was draining since they felt they had to entertain the visitor. There was a great desire expressed for visits by someone who "really understood" and who would come regularly. In many cases caregivers said they felt guilty that they were making what they felt to be negative comments about their church, minister or priest.

When people became caregivers suddenly as a result of a crisis or serious illness emotional support was much better and much more likely to be offered. Outreach to both caregivers and care receivers was also better near Christmas. Those who were caregivers over a period of years generally felt that others stopped being aware of their needs.

The majority of caregivers did not receive the emotional support they needed from their families. Some had no family members living close enough to spend time with them, or had no family members physically or emotionally well enough to meet their emotional needs. Several voiced their upsets that not only were their emotional needs not met but that they were criticized by other family members for not doing more for the care receiver. Some caregivers felt resentment from spouses or children because of their caregiving role. Many felt that other family members did not understand the demands on their time and energy or even their desire to care for their loved one. A few expressed that out of concern for the caregivers, other family members wanted them to place their loved one in a long term care facility even when

the caregiver felt this was not at all acceptable or necessary. Therefore, they tended not to ask for help or discuss the situation freely for fear that more pressure would be put on them to follow these wishes. Parents caring for the needs of a child with life-long physical and/or emotional challenges did not receive good emotional support from most.

There were, however, some caregivers who felt understood and supported by other family members and had their emotional needs met either in person or from a distance. Some spouses felt very supported by their partners who were not only good sounding boards but also helped in decision making and sharing many of their caregiving duties. There were also some parents who felt very supported by their children for the same reasons. In a few instances caregivers had close friends who were as supportive or more supportive than family members.

c) Can you recognize signs of stress and exhaustion, e.g. sleeping poorly, crying frequently, irritable, feeling overwhelmed, feelings of resentment, inadequacy?

All caregivers agreed that they noticed some or all of these signs as a result of caregiving. Most noticed them at the time although some didn't recognize how they were feeling until some time later or until it was pointed out to them by someone else. For most, the level of these feelings was in direct proportion to the demands on their time and energy by both the care receiver and others. About 1/5 of the caregivers volunteered that they are, or were, being treated for depression as a result of being caregivers. This was not asked and therefore it is likely that many more were affected in this way. One caregiver mentioned that his blood pressure is elevated due to the stresses of caregiving and he therefore requires medication for it.

d) Can you maintain your health through exercise, diet and regular medical check-ups?

All caregivers stated that they were able to see a doctor when needed although many tended to avoid anything seen as an extra visit due to the time it would take. All said that caregiving did not prevent them from eating properly but some felt the added stress often meant that they leaned more toward comfort foods.

Most 24/7 caregivers said they were not able to get the exercise they needed due to not being able to get outside nearly as often or for as long as was needed. Some said that weariness had sapped their desire to exercise even when there were opportunities. Although many could and did take the care receiver for walks, the caregivers still longed for times to go on their own.

e) Are you eligible for compassionate leave through Employment Insurance (1-800-622-6232)?

Only one caregiver took a compassionate leave from work and then returned after the death of his loved one. One caregiver retired early due to caregiving needs but the rest had already retired, were not working outside the home or were not eligible due to their situation.

f) Are you eligible for caregiver tax credit (1-800-959-8281)?

About half of the caregivers interviewed were not aware of this tax credit. Many caregivers felt they did not meet the necessary requirements but some were going to check into it or have the person who prepared their income tax do so.

III. Assess your Pastoral Needs

a) Have you ever evaluated your desire and ability to provide care?

Although almost all caregivers interviewed had not done a formal assessment of themselves, all had previously given thought to their desire and ability to provide care.

Do you feel that providing care is something you have to do?

Caregivers struggled with this question, believing that to some degree all of us have to or should provide for the needs of our loved ones which at some point is apt to include becoming a caregiver in at least some capacity. For a small minority there was a weary resignation to the reality that there wasn't anyone else to do it, although they then clarified that even so, they would want to look after the care receiver but with more help. One female caregiver did feel resentment that her brothers assumed she should be the caregiver of their mother because she was the girl in the family and that's what her role should be. She also felt resentment that her mother had been dependent on others most of her life even when her physical health had been good. There was a definite tendency for the males in the family to feel that caregiving was something that women would do although interviews were conducted with men who had become caregivers to their loved ones and felt it was their responsibility.

None of the caregivers interviewed questioned their overall ability to provide care although a few did voice questions about how long they could continue to give the care necessary, especially if the needs increased. For some caregivers there was a natural concern expressed about what would happen if they were no longer physically or mentally capable of providing care. Many caregivers felt they could or should be doing more for the care receiver but also recognized that the care they did provide was better than what their loved one would receive in a long term care facility. However, some were open to the possibility that in the future institutional care might be necessary and could have benefits to the care receiver according to his/her condition. Some caregivers expressed their need to set some limits as far as ensuring that they could have time with their spouse, children or friends, feeling that the more they gave the care receiver then the more was expected and even taken for granted.

One caregiver was extremely concerned about the future possibly of her spouse needing to go to a long-term care facility a long distance away (over 125 km.) from where they live due to the type of care he would need (kidney dialysis). Caregivers whose loved ones need to be in a secure unit due to having Alzheimer's disease are also limited by which long-term facilities can provide such care.

Did you seem to fall into this role by accident?

Many suggested that the amount of care given had increased gradually and that they were surprised at the huge amount of time and energy it now took.

b) What are some of the ways you deal with feelings of guilt or inadequacy for the caregiving role?

Those interviewed had many ways of working through their negative feelings which resulted from the demands and expectations of being caregivers. There was some overlap in the answers given to this question and the following one which looked at spiritual awareness. Although an attempt has been made to separate the two, both lists of answers should be considered. Some caregivers indicated that they hoped their answers to this question would help others and that they would be interested in hearing how other caregivers cope(d). Therefore, all answers have been included with duplication removed:

- talking to another family member
- talking to a friend
- praying
- focusing on the blessings of caregiving
- reminding oneself that there is limited time left with the care receiver
- knowing that it was the caregiver who was making the care receiver as comfortable as possible
- attempting to see him/herself in the care receiver's situation and trying to understand the care receiver's fears
- a belief in wanting to give to others
- trying to think things through; backing off and buying time
- trying to think ahead to avert or be prepared for highly stressful situations
- enjoying a pet or pets
- stopping what you're doing and taking a break
- studies which focus on compassion
- trying to rationalize the problems in order to deal with them
- letting go of extra responsibilities if at all possible
- seeing God present in the situation
- reading a book about anger helped one caregiver "own it and deal with it"
- having a nap if possible
- getting grumpy and then getting on with what needs to be done
- seeing a doctor or counsellor if needed
- taking medication if necessary to help with depression
- getting away from the situation even if just briefly – a change of scenery
- talking and/or venting to someone who understands (not necessarily a friend or family member)
- talking about stressors before they build up too much
- crying
- going for a walk
- having an optimistic attitude
- turning the phone off and just resting and trying to relax for half an hour
- being visited or having a phone visit
- just getting outdoors
- encouraging care receivers who are too dependent to take taxis more often if their health permits it
- recalling wonderful childhood made possible by the care receiver

- watching videos and travelogues
- playing cards or board games, sometimes with the care receivers even if they are no longer able to play well
- doing crossword or jigsaw puzzles, alone or with the care receivers or others
- being around others, even if it's just walking through the mall
- focusing on others and listening to their problems or even doing things to help if time and energy permit
- getting involved in other volunteer work (when the situation makes that possible)
- going to yoga, tai chi, exercise classes or to work out
- if at all possible, hiring someone to help with cleaning or other chores
- enjoying hobbies or other interests (caregivers mentioned gardening, crafts, pressing flowers, scrapbooking, photography, sewing, rug hooking, woodworking, curling, bowling, genealogy, refinishing furniture, needlework, cello lessons, quilting, playing the piano/organ, singing, horseback riding, dancing, swimming, playing dominoes)
- journaling
- writing
- going out to eat
- encouragement from others
- watching television
- reflecting on other difficult times in life and the coping skills learned then
- going for a drive
- taking advantage of massage therapy, reflexology and other services available to caregivers in the Sunshine Room at the VG if the care receiver has to go for treatment or check-ups in Halifax, or paying for these services locally
- using the computer
- Quakers are benefiting from their Committee of Care and/or Clearness Committee, formed specifically to help give them direction and care in their situation
- reading
- attending a caregiver support group
- working to maintain old friendships
- going shopping
- getting absorbed in the newspaper
- reflecting on what is good in life
- poetry
- listening to music
- using a "magic bag" to soothe and relax tight muscles
- going to a movie or performance
- recognizing there are personal limits
- wanting to honour the commitment the caregiver chose to make
- going to groups or workshops addressing issues or conditions the caregiver is trying to deal with
- having a quiet time
- listening to the radio
- reading to the care receiver

- knowing there is prayer support
- listening to books on tape
- going camping, even for a weekend
- getting away for at least a few days if ever possible
- finding a distraction
- attacking some household chore; one caregiver said her stove had never been as clean!
- taking the dog outside
- biking, skiing, snowshoeing
- revisiting a place from your past
- trying to maintain a sense of humour
- reminding oneself that there will again be better days – the care receiver's good days always give the caregiver a lift

c) What are some of the ways you find helpful in increasing and strengthening your spiritual awareness? (Facilitating a sense of wholeness, sustaining a sense of wholeness in living, feeling God's presence)

- praying
- reading the Bible
- attending church services
- having a mentor or spiritual advisor
- allowing others to be involved in the care receiver's life - one caregiver gave the care receiver a room which was the focal point of the home so that friends would drop in often and so the care receiver could see from her window what was going on in the community
- attending small groups, Sunday school, Bible studies or other church groups
- talking to the care receiver who has a strong faith
- being with other family members
- being with friends who have a faith and share beliefs
- watching the ocean and sunsets
- receiving pastoral visits
- recognizing special blessings which have come from the present situation
- reading books on spirituality
- enjoying the view from the window
- having daily devotions, either alone or with others
- being outside with nature
- listening to hymns or inspirational music
- talking to wise older people in the church who were genuine and instilled confidence and hope
- meditation
- going to a spiritual retreat
- receiving communion at church or at home
- journalling
- planting, maintaining and enjoying a memorial garden which was begun when the care receiver was still living and had input into it
- reading books of prayers

- following the spiritual progress of grandchildren enhanced that of the caregiver
- seeing how God has enabled the caregiver or been present with the care receiver
- watching television programs which have a spiritual focus
- listening to radio programs which have a spiritual focus (one caregiver enjoys “Tapestry” on CBC each Sunday afternoon)
- visual symbols
- saying grace at meals
- walking in the woods
- learning from the whole experience of being a caregiver
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- One caregiver said it was not possible to increase her spiritual awareness due to the ongoing stress of caring for someone with Alzheimer’s disease prior to the care receiver’s placement in a long-term care facility.

d) What do you hope to provide for the person you are caring for in terms of spiritual well-being?

- nurture their faith in whatever way best suits their current condition
- surround them with as much love as possible
- treat the care receiver with respect regardless of their condition
- see that the care receiver gets to church if or whenever possible
- have more visits from the minister or priest
- have deacons/elders/pastoral care team bring in communion regularly if the care receiver isn’t able to go to church
- make sure there is ongoing contact with the care receiver’s church; one caregiver very concerned about visits to the home of frail, elderly care receivers by Jehovah’s Witnesses

Several caregivers stated that due to their care receiver’s level of dementia, all anyone could do now is spend time with them and show them they are cared about and not forgotten.

How will you provide for the spiritual well-being of the care receiver?

- request tapes of church services
- continue to provide devotional materials for the care receiver’s use
- caregiver has open dialogue with the care receiver about faith and spiritual matters
- caregiver lends care receiver any resources she has which might be of help or interest
- caregiver desires that care receiver take baptismal classes when ready
- have the local minister make sure the care receiver receives pastoral care from the chaplains of hospitals or nursing homes or local clergy; one care receiver was totally missed when in hospital in Halifax for a fairly lengthy stay
- make sure care receiver can watch church services or faith related programs on TV if desired

- read the Bible to the care receiver and discuss it
- play hymns or enjoyable music
- encourage the care receiver's friends and family to visit them

e) What could our churches be doing to help you in your role as a caregiver? (All suggestions have been included whether already offered by an existing organization or not):

- continually find ways to welcome and include anyone with special needs in our churches
- raise awareness about caregiving by educating our congregations and communities
- have one person caregivers can call – sometimes they don't know who or where to call for what they need and sometimes they just need to talk to someone who understands
- offer to take the care receiver out for a drive; it provides a change for them and gives the caregiver a break
- “the church has to continue to be a vital part of the life of care receivers no matter what their condition” – do whatever it takes to ensure that
- have case managers to help caregivers plan and carry out care
- provide those who will come in to be with the care receiver so the caregiver can go out or just have a rest; many 24/7 caregivers have their sleep interrupted nightly
- list all available local health services - have an up-to-date directory
- have a caregiver support group
- don't decide what caregivers want without asking them!
- offer to help, and offer again if it isn't accepted at first – to sit, do yardwork, do household repairs, do housework or anything else you feel you could do; specific offers are more likely to be accepted
- whenever possible, include the care receiver in normal activities even if they have some challenges
- have a place where caregivers can get together and bring their care receivers with them
- create a network of caregivers so they can identify and talk to others in similar situations
- regularly visit the caregiver at a time convenient to them (not interrupting the care receiver's times of personal care, rest or meals)
- provide household safety information
- pray for the caregivers and not just the care receivers and let them know about it
- help caregivers dealing with wheelchairs or other assistive devices when they have the care receiver with them; remember that many of these things have to be folded up and sometimes taken apart to be transported and lifted in and out of vehicles
- offer to take both caregiver and care receiver to church or special events; by the time the caregiver has both of them ready they are often tired out
- have an adult day program locally (for care receivers)

- invite the caregiver out or to your home, providing transportation and/or respite care if needed
- invite both caregiver and care receiver out or to your home
- invite the care receiver out or to your home if their condition makes it possible
- regularly visit my loved one at home and become his/her friend
- regularly visit my loved one now residing in long-term or special care; set up extra visitation if the caregiver is ill or away or if the care receiver is critically ill
- regularly visit my loved one in the hospital
- develop a caregiver website focusing on local resources
- advocate for the caregiver or care receiver when they need one
- have a local resource person available
- have an online support group
- have health-related resource material (about medical conditions)
- offer workshops on caregiving and related issues
- if the caregiver still has children at home, offer to look after them in your home sometimes, especially if the care receiver is ill
- offer sincere words of affirmation and encouragement
- help by driving the care receiver to church or medical appointments (getting to those in Halifax particularly stressful and tiring)
- drive caregivers who don't have transportation
- offer to get groceries, pick up medications or run errands
- show some interest!
- make churches and halls more accessible to those with mobility challenges or in wheelchairs
- help with paperwork relating to caregiving responsibilities or income tax
- offer to go with the caregiver when looking into care alternatives
- offer to be with the caregiver when the care receiver is being assessed
- offer to go with the caregiver and care receiver to medical appointments
- have respite homes and affordable respite care
- offer financial assistance when a care receiver's condition requires high medical costs
- co-ordinate help from friends and neighbours
- do supervised baking with several care receivers at a time; this helps raise their morale and also helps by providing food they can enjoy
- read to the care receiver
- have Bible studies or small groups in seniors' housing where many could benefit
- taking books, tapes and videos from church or public libraries to the caregivers' homes
- remembering to give pastoral care to the caregiver and not just the care receiver
- bringing in a meal and staying to eat it with caregiver and care receiver
- taking baked things from time to time or a prepared meal to leave with the caregiver
- somehow recognize caregivers in church or in the community; have a caregiver luncheon and give them a small gift or flower

- keep caring for the caregivers after their loved one has gone to a long-term care facility
- don't forget the caregiver after their loved one has died; there is often mental and physical exhaustion as well as grief
- be sure the minister or priest makes pastoral visits too and not just lay visitors
- mail or bring church bulletins or tapes of the church services if desired
- get care receivers to groups they might enjoy and take them back home
- have special teas or social times so those who are housebound most of the time can get out and see others
- provide up-to-date lists of those who will sit with the care receiver or volunteer their talents to help with household tasks
- develop up-to-date lists of qualified care providers in the area the caregiver can hire to help – especially important when there is an emergency
- bring children to visit care receivers who would enjoy seeing them
- bring pets to visit care receivers who would enjoy them and where they are allowed
- keep talking to care receivers who have dementia
- identify yourself when calling; age and stress sometimes mean the caregiver doesn't recognize your voice or recall your name
- offer to help care receiver do daily exercises
- send caregivers cards every so often to let them know they are thought of, prayed for and appreciated
- personalize messages on get well, thinking of you or sympathy cards
- phone caregivers to see how they are doing
- keep caregivers aware and up-to-date on any legalities pertaining to caregivers or care receivers
- visibly put into practice what the church is supposed to be about which is to love one another
- consider the load the caregiver carries before asking them to help with church or community functions but don't neglect asking them for help in small ways if they seem to want to
- begin a respite fund to help caregivers who can't afford to pay for a break
- remember that some caregivers are new to the community or have returned after many years away – provide them with helpful information such as which drug stores and grocery stores provide free delivery, when senior discount days are, when and where health clinics are held, when and where food and clothing banks are located and open
- have caregiver guilds within each church so caregivers can identify one another
- offer personal mentoring by qualified people
- educate seniors in particular about recognizing and taking symptoms seriously
- educate caregivers about caregiver abuse by care receivers
- involve university students, as part of their programs or just create the desire to help and get to know both caregivers and care receivers
- involve our youth by matching them with care receivers, either at home or in long-term care facilities, who would appreciate visits

- involve teens or older students to help caregivers do heavy lifting (one caregiver is not able to move her lawn furniture in and out as seasons change)
- have a fun group for those 50+
- hold workshops with speakers addressing caregiver issues and interests
- have prayer and sharing groups
- develop sustainable caregiver support – fund with endowments
- be sensitive to the caregiver’s situation; do a lot of listening
- sometimes just make a social visit and share the “outside” world with the caregiver if he/she desires that; not all caregivers want to talk only about caregiving and/or medical conditions
- educate caregivers that respite breaks are essential; some caregivers feel they are abdicating their responsibilities or not living up to promises made to the care receiver if they dare to take some time off
- provide the caregiver with the names of three people who could be called and would be willing to be supportive in various ways
- show a genuine interest in the elderly – get to know them and learn about their era
- encourage caregivers to ask for help
- realize that just getting out long enough to have a haircut or get one’s hair done can be a real perk

Other comments or concerns offered by the caregivers interviewed:

- offer volunteer training – people fearful because they don’t understand the condition of the care receivers or what might be required of them if they volunteered
- encourage caregivers to have a will and to be sure the care receiver has a will
- teach about power of attorney and living wills
- people don’t visit the care receiver because he/she can no longer give anything back to the visitor
- feels nobody wants to commit or become involved
- care receiver can’t get a doctor
- lack of two bedroom rental units for seniors in the area
- no local facility for couples who need different levels of care which means they almost always have to be separated
- need an interim care facility for those convalescing