First Link Premier lien

QUALITY ASSURANCE EVALUATION REPORT:
THE FIRST LINK DEMENTIA NETWORK &
THE DEMENTIA TRANSITION PROJECT

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INTRODUCTION

The First Link Dementia Network and the Dementia Transition Project are a collaborative initiative led by the Alzheimer Society of British Columbia in partnership with the Vancouver Island Health Authority. Focused on building capacity to address existing needs, these two innovative pilot projects are linked with the Seniors at Risk Integrated Network (SARIN) developed in Victoria, British Columbia, and work to strengthen and extend the continuum of community-based services available to people with dementia and their families. Specifically, the First Link Dementia Network is an outreach project that connects people with a diagnosis of dementia to key resources early on in the disease, whereas the Dementia Transition Project provides support and wellness programming for family caregivers.

Important elements of First Link include direct referrals, proactive contact, connections to resources and ongoing follow up throughout the entire progression of dementia. At the time of diagnosis, physicians and other health professionals refer patients and their families directly to First Link. The First Link Coordinator then proactively contacts the patients and their families to offer information and link them to education programming and support services from the Alzheimer Society Resource Centre in Victoria as well as other community resources.

The Dementia Transition Project builds upon the education and support services provided through the Alzheimer Society, and is designed to address and support family caregivers' experience of loss and grief, their fears and concerns, and to help them prepare for the future. Through a 6-part "Coping with Transitions" education series, family caregivers will be provided with the opportunity to identify tools & strategies for weathering the myriad of these transition losses through a group facilitated environment.

Evaluation of the First Link program and the Dementia Transition Project consisted of review of referral and program records; evaluation surveys of clients, physicians and health care professionals who made referrals to First Link; and an efficacy evaluation study on the "Coping with Transitions" group education and wellness program. The evaluation not only serves to reveal whether the two projects achieved the overall program goals, it is also a formative evaluation that emphasizes service outcome as well as program learning and effectiveness.

HIGHLIGHTS

CLIENTS OF THE FIRST LINK PROGRAM

- 71% of respondents felt that it was reassuring to know that they can call First Link for information, programs and services which can help them to cope with their or their family members' dementia.
- 80% of respondents indicated that they know more about dementia-related services and programs that are available in the community upon joining First Link.
- 70% of respondents felt that they have benefited from participating in the First Link program.
- 88% of respondents indicated that they would recommend First Link to people with dementia and their family members.

REFERRING AGENCIES OF THE FIRST LINK PROGRAM

- 90% of respondents felt that they are more aware of the services offered by the Alzheimer Society as well as other dementia-related community services a result of First Link.
- 70% of respondents felt that clients have benefited from participating in First Link.
- 100% of respondents felt that the First Link program has benefited their practice/service.
- 100% of respondents indicated that they would strongly recommend First Link to other health professionals.

PARTICIPANTS OF "COPING WITH TRANSITIONS" EDUCATION SERIES

- Upon completing the series, a clear trend of improvement among participants' overall well-being was observed, including: improvement in subjective physical and mental health; reduction in depressive symptoms; lower levels of perceived caregiver distress; greater levels of perceived social support; and greater satisfaction with life.
- Participants also displayed statistically significant improvements in their overall spiritual health; in particular, their reported level of disorientation was reduced while feelings of tranquility and resilience were amplified.
- 89% of participants felt that the education series had helped to identify their warning signs of imbalance, stress, overload and burnout, and provided them with some strategies and tools for their own self-care.
- 93% of participants felt that they have benefited greatly from participating in the education series, and would highly recommend the education series to other caregivers in the dementia journey.

BACKGROUND

According to the Provincial Dementia Service Framework Working Group[1], British Columbia, along with the rest of Canada, is experiencing significant population aging. As the chance of developing dementia increases significantly with age, population aging is therefore correlated with increases in the number of people affected by dementia. It is estimated that in 2006 $1.39 billion was spent in BC on direct care related to dementia. These costs are projected to increase to $1.97 billion by 2016 (in 2006 dollars). This cost estimate does not include acute care costs and the costs to individuals with dementia and their families.

The extent of the economic burden created by a high prevalence of dementia reinforces the need for a system-wide approach to ensuring that individuals with dementia and their families receive optimal care, drawn from best practice. It also points to the need for upstream activity to help prevent dementia and to help those who are at risk for or diagnosed with the condition remain healthy for as long as possible. Given this, seven significant barriers to the provision of optimal dementia care in British Columbia were identified in the BC Dementia Service Framework[1]. Among others, the most prominent barriers include: 1) a critical gap in the systems' capacity and ability to address the clinical and support needs of people with dementia and their families/caregivers; and 2) a critical gap in the formal integration, collaboration, and communication across care settings, between health care providers, and across health authorities.

In an attempt to address these provision barriers so as to connect and establish a seamless array of community-based support and education services for people with dementia and their families, the Alzheimer Society of B.C. in partnership with the Vancouver Island Health Authority developed the First Link Dementia Network and the Dementia Transition Project in 2008. Focused on building capacity to address existing needs, these two innovative pilot projects are linked with the Seniors at Risk Integrated Network (SARIN) developed in Victoria, British Columbia, and work to strengthen and extend the continuum of community-based services available to people with dementia and their families. Specifically, the First Link Dementia Network is an outreach project that connects people with a diagnosis of dementia to key resources early on in the disease, whereas the Dementia Transition Project provides support and wellness programming for family caregivers.

DESIGN OF PROJECTS

The First Link Dementia Network and the Dementia Transition Project are designed not only to link seamlessly to one another, but with other supports within the community as well. The projects operate from the Alzheimer Society of B.C.'s Victoria Resource Centre.

First Link Dementia Network Design

The primary goal of the First Link Dementia Network is to co-ordinate a first response strategy for people newly diagnosed with dementia and their families. A core component of this strategy is to develop a comprehensive network of service providers. Using an outreach model, the project identifies and develops a database of service providers and establishes meaningful links between the project and the service providers as well as a commitment to a referral process. Partnerships fostered through the development of a network of health professionals and community agencies ensures more effective utilization of resources. Through First Link, individuals and their families are formally referred directly to the Alzheimer Society of B.C. as soon as possible after diagnosis. A First Link Coordinator proactively contacts the families and provides information about the disease, informs clients about support services, and offers connections to education programming and support services from the Alzheimer Society Resource Centre in Victoria as well as other community resources. Individuals and families are linked early on in their journey. Knowledge and support makes the journey easier and enables families to cope with crises more confidently. First Link is modeled on similar First Link pilot projects in Ontario.

Dementia Transition Project Design

The Dementia Transition Project is a new concept designed to address and support family caregivers' experience of loss and grief, their fears and concerns, and to help them prepare for the future. More specifically, the intervention model, "Coping with Transitions in Dementia Caregiving: Dimensions of Loss and Grief", is a 6-part education series that explores the loss and grief issues of the caregiving experience in order to identify tools & strategies for weathering the myriad of these transition losses. The format for each session includes presentation of information, a stress management/relaxation experience, as well as ample time for group dialogue and personal exploration. Group size is limited to no more than 8 participants to ensure adequate time for discussion. This component of the project is developed and facilitated by trained counsellors.

PROJECT GOALS

- To establish a direct referral system that links newly diagnosed individuals with dementia and their families to a continuum of care through a community of learning, service and support.
- To develop a transition project that:
    - Provides an integrated model of community support for family caregivers; and
    - Will fill an identified gap in support and education services currently provided by the Alzheimer Society of B.C., other community agencies and formal health care system services.

Objectives:

- Strengthen and formalize relationships between dementia-related health professionals and community agencies.
- Develop a referral system process that facilitates early intervention and proactive outreach.
- Provide education for physicians and other health care professional in using First Link.
- Implement a public awareness strategy to inform the community of First Link.
- Connect people with dementia and their families to interventions and support as soon as possible after diagnosis.
- Provide a connection to education and support for the family caregiver at all stages of the disease with a focus on early transitions; support includes provision of information, education and emotional support.
- Provide programming for caregivers focusing on well-being and preparation for the remainder of the journey.

EVALUATION

With the implementation of the First Link Dementia Network and the Dementia Transition Project, an evaluation of their functions and efficiency is required. First, this evaluation has to reveal whether the two pilot projects achieved the overall program goals. Equally important, it is also a formative evaluation with emphasis on service outcome as well as program learning and effectiveness.

Against this background, and given that the complexity of the First Link Dementia Network and the Dementia Transition Project cuts across connective, educative and supportive dimensions, a controlled experimental design of evaluation is not feasible. Instead, a pragmatic formative evaluation paradigm is adopted as it stresses a practical, problem-solving orientation to program evaluation. Based on a pluralistic evaluative approach, this study employed a mix of quantitative and qualitative data, derived from a variety of sources and stakeholders. They include:

- Referral statistics collected by the working group of the First Link Dementia Network and the Dementia Transition Project;
- Quantitative data obtained from the First Link Evaluation Survey (Appendix 1) which includes an Intake Assessment Survey and a Follow-up Evaluation Survey completed by 41 participants of the First Link Dementia Network;
- Quantitative and qualitative data obtained from the Referring Agency Evaluation Survey (Appendix 2) completed by 14 referring agencies who participated in the First Link Dementia Network; and
- Quantitative and qualitative data obtained from the Dementia Transition Project Efficacy Evaluation Study (Appendix 3) on the “Coping with Transitions” group education and wellness program based on a cohort pre and post research design with 27 participants.

RESULTS ON FIRST LINK SERVICE OUTPUT

Referrals Statistics

- 121 families were referred to First Link between June 2008 and March 2009.
- 21% of families were referred directly by health professionals connected to the new Seniors at Risk Integrated Network of the Vancouver Island Health Authority (this 21% includes health professionals also reflected in the statistics below, i.e. case managers, physicians, nurses connected to SARIN)
- 39% of families were referred by diagnostic agencies in Victoria, B.C.
- 34% of families were referred by Case Managers
- 11% of families were referred by other health professionals (i.e. nurse, occupational therapist, social worker)
- 9% of families were referred directly by their family physicians.
- 4% of families were referred by community agencies
- 3% of families contacted First Link on their own.
- Response time of First Link coordinator making the first call to referrals varied from same day to four weeks. For those newly diagnosed, First Link waits 3 to 4 weeks before calling to allow time to adjust to the diagnosis; others are contacted as soon as possible.

Participation in the First Link Program

- 93% of families are considered active, meaning they accepted the referral and express interest in continuing contact with First Link
- 7% of families are considered inactive:
    - 3 families were discharged due to death of the person with dementia.
    - 3 families were discharged due to death of the caregiver and the person with dementia then moving from the area
    - 1 family moved out of area and was referred to another Alzheimer Resource Centre for support
    - 2 families declined to participate in the program.

RESULTS FROM THE FIRST LINK EVALUATION SURVEY

METHODS

A quality assurance evaluation survey (Appendix 1) was conducted to assess the quality of service rendered by the First Link program from the perspective of its clients. Particularly, this survey examined the overall effectiveness of First Link in expanding clients' support network through elevating their knowledge of community resources. Upon first contact with the First Link program, all clients were invited to complete an Intake Assessment Survey that elicited information regarding their knowledge of the programs and services rendered by the Alzheimer Society of B.C. and other resources available in the community. Upon 3 months of joining First Link, clients were again invited to complete a Follow-up Evaluation Survey that elicited information regarding the types of service they had received and were referred to, as well as their subjective ratings on the quality of service rendered by the First Link program. During the period of evaluation, a total of 41 clients, 4 persons with dementia and 37 family caregivers, had successfully completed the survey (N=41).

FINDINGS

Nature of respondents

- Of the 41 survey respondents, 4 were persons with dementia and 37 were family caregivers.
- Survey respondents indicated either they or their family members had been diagnosed between 1998 and 2008, with over 50% being diagnosed in 2008.
- 68% of respondents indicated they had not received any formal information about dementia and related issues (i.e. booklet, handout) prior to First Link.

Knowledge of Alzheimer Society Programs Prior to First Link

- 85% of respondents indicated that they had heard of the Alzheimer Society prior to First Link, but only 33% or 12 respondents knew about the types of programs and services offered by the Society.
- Among those who knew about the Alzheimer Society's programs and services, 2 respondents had participated in a Caregiver Support Group and had obtained useful information from the Society's library.
- In terms of the reason for not having participated in such programs and services, 7 respondents indicated that their diagnoses were far too recent; 2 indicated that they were unable to leave their family member alone; and 1 indicated that the programs were not of interest to him/her.

- 88% of respondents indicated that they were interested to participate in the programs and obtain services offered by the Alzheimer Society.
- Programs and services of interest include: Newsletter (71%), Information/Library (49%), Support Group – Caregiver (37%), Education – Dementia Series (28%), Education – Shaping the Journey (20%), and Support Group – Early Stage (5%)

Knowledge of Other Community Resources Prior to First Link

- 78% of respondents indicated that they were not aware of other services available in the community prior to First Link.
- Among the 9 respondents who were aware of the services available in the community, 2 had participated in an Adult Day Program; 5 had received Home Support; 1 had received Respite Care; and 5 had obtained services from various care facilities, the SARIN team, Veteran's Affairs and an Assisted Living facility.
- 52% of the respondents indicated that they were interested to participate in other programs and services that are available in the community.
- Programs and services of interest include: Family Caregivers Network (20%), Home Support (15%), Adult Day Program and Respite Care (7%), Hillside Wellness Centre (5%), and Memory PLUS (5%).

Linkages to Alzheimer Society Programs

- Upon 3 months of joining First Link, 76% of respondents indicated that First Link helped them to connect with the Alzheimer Society's programs and services.
- The Alzheimer Society's programs and services most frequently connected with include: Newsletters (73%), Information/Library (44%), Education – Dementia Series (22%), Individual Support (17%), Education – Shaping the Journey (12%), Support Group – Caregiver (10%), and Coping with Transitions (5%).

Community Linkages

- Upon 3 months of joining First Link, 25% of respondents indicated that First Link helped them to connect with community resources.
- The community services most frequently connected with include: Home & Community Care and Residential Care case managers (7%), Adult Day Program (7%), Home Support (5%), and Family Caregivers Network (5%).
- 63% of respondents reported that they contacted their family physician if they have a concern or question about Alzheimer's disease, dementia or caregiving. The next most

frequent contacts were reported to be with: Case Manager (12%), family/friends (10%), Alzheimer Society (7%), and First Link (5%).

Evaluation of the First Link Program

- Upon 3 months of joining First Link, all respondents indicated that they had received formal information about dementia and its related issues from First Link.
- 81% of respondents felt that it was important for First Link to call them rather than having to make the call themselves.
- 71% of respondents felt that it was reassuring to know that they can call First Link for information, programs and services which can help them to cope with their or their family members' dementia.
- 27% of respondents had contacted First Link for information, programs and services (client-initiated call).
- 80% of respondents indicated that they know more about dementia-related services and programs that are available in the community upon joining First Link.
- 95% of respondents indicated that the First Link bulletin provided them with information about programs that are available in the community.
- 85% of respondents indicated that they know more about Alzheimer's disease/dementia through the information package received through First Link.
- 70% of respondents felt that they have benefited from participating in the First Link program.
- 88% of respondents indicated that they would recommend First Link to people with dementia and their family members.

RESULTS FROM THE REFERRING AGENCY EVALUATION SURVEY

METHODS

A quality assurance evaluation survey (Appendix 2) was conducted to assess the quality of service rendered by the First Link program from the perspective of its referring agencies. Particularly, this survey examined the overall effectiveness of First Link in providing health professionals a point of referral for their clients as well as expanding their knowledge of available community resources. During the evaluation period, 20 referring agency survey were mailed out and 14 were returned, yielding a response rate of 70% (N=14).

FINDINGS

Nature of respondents

- Of the 12 survey respondents, 5 were case managers, 5 were family physicians, 2 were social workers, 1 was a community agency staff, and 1 was a nurse practitioner.
- 50% of the respondents indicated that they first learned about First Link through presentations and meetings, 25% learned about First Link through a colleague, and 25% learned of First Link through mailed referral packages.

Referrals

- 59% of respondents indicated that before the introduction of the First Link program, they referred 1-7 clients per month to the Alzheimer Society.
- 90% of respondents indicated that since the introduction of the First Link program, they referred 1-7 clients per month to First Link.
- Reasons for referral: (more than one response allowed)
  - 100% of respondents indicated that support was the primary reason for referral.
  - 50% of respondents indicated that education was the primary reason for referral.
  - 52% of respondents indicated that information was the primary reason for referral.
  - 33% of respondents indicated that links to community services was the primary reason for referral.
- 90% of respondents indicated that they encountered no obstacle to making a referral to First Link. For those who had encountered obstacles, the obstacles are the lack of time and the lack of referral form.
- 45% of respondents indicated that 1-3 clients declined a referral to First Link.
- Reasons for decline: (comments provided by clients)
  - “I don’t think it will help my situation”.

  - "I have no time to leave my family member with dementia".
  - "I did not feel ready for service / I already had too many people contacting me".
  - "I have already contacted the Alzheimer Society".

Evaluation of the First Link Program

- 100% of respondents felt that making referral to First Link was easy and simple.
- 90% of respondents felt that that referral package provided sufficient information about First Link.
- 90% of respondents felt that they are more aware of the services offered by the Alzheimer Society as a result of First Link.
- 90% of respondents felt that they were more aware of other dementia-related community services through the First Link e-bulletin.
- 70% of respondents felt that clients have benefited from participating in First Link, especially knowing that ongoing support and information are available.
- 100% of respondents felt that the First Link program has benefited their practice/service. Comments of how First Link helped included:
  - "Caregivers immediately appreciate the support from First Link, while clients agreed that being connected to a service that understands dementia is beneficial".
  - "First Link easily connects clients to resources in the community".
  - "First Link has given me an avenue for referrals".
  - "It is great having an ongoing service for clients and families that reaches out to them. Often families do not follow through with contacting the Alzheimer center themselves".
- 100% of respondents indicated that they would strongly recommend First Link to other health professionals.

RESULTS FROM THE DEMENTIA TRANSITION PROJECT EFFICACY EVALUATION STUDY

METHODS

An evaluation study (Appendix 3) was conducted to assess the efficacy of education series rendered by the Dementia Transition Project from the perspectives of its participants. Adopting a pre-post single group research design, this study examined the overall effectiveness of the "Coping with Transitions in Dementia Caregiving: Dimensions of Loss and Grief" education series in elevating participants' physical and psychological well-being, quality of life, and level of adjustment in coping with the loss and grief associated with dementia. Subjects in this study included 27 participants that have successfully completed the "Coping with Transitions in Dementia Caregiving: Dimensions of Loss and Grief" education series (N=27). Upon obtaining informed consent, participants were asked to complete a structured questionnaire prior to the start of the education series (T1), and again after they have completed the series (T2).

Outcome Measures

The structured questionnaire comprised of a series of standardized assessment tools that include:

1) Health Questionnaire Short Form (SF-12)[2]: a 12-item self-report measure of subjective health status, with the 2 subscales of Physical Health and Mental Health.
2) Center for Epidemiological Studies-Depression Scale (CES-D): a 20-item self-report measure of depressive symptoms.
3) Caregiver Self-Assessment Questionnaire (CSAQ)[3]: an 18-item self-report measure of caregiver distress, with the 3 subscales of stress symptoms, subjective level of stress, and subjective health status.
4) Multidimensional Scale of Perceived Social Support (MSPSS)[4]: a 12-item self-report measure of social support, with the 3 subscales of support from significant others, support from family and support from friends.
5) Satisfaction with Life Scale (SLS)[5]: a 5-item self-report measure of life satisfaction.
6) WHO Well-being Index (WHO5)[6]: a 5-item self-report measure of subjective well-being.
7) Body-Mind-Spirit Well-Being Inventory - Spirituality Scale (BMSWBI-S)[7]: a 13-item self-report measure of spiritual health, with the 3 subscales of Tranquility, Disorientation, and Resilience
8) A series of program evaluation questions, both quantitative and qualitative, were also incorporated into the structured questionnaire so as to provide participants with the opportunity to subjectively rate and comment on the quality of the education series.

Statistical Analysis

Pair-sample T-tests on each outcome measure were conducted to assess the effect of the "Coping with Transitions in Dementia Caregiving: Dimensions of Loss and Grief" education series.

FINDINGS

Nature of participants

- The mean age of the participants was 64.44 years with a range from 47 – 85 years.
- 80% of participants were female; 20% were male.
- 94% of participants had graduated from high school, while 42% had obtained a university degree.
- 68% of participants were retired or a homemaker, 24% held full-time employment, and the remaining 8% held part-time employment.
- 27% of participants had no children, 4% had 1 child and 69% had 2 or more children; the age of children ranged from 19 – 61 years.
- Study participants indicated that their family members had been diagnosed between 2001 and 2008; the mean age of their family member was 77.85 years with a range from 54 – 95 years.
- 31% of participants indicated that their family member had been diagnosed with Alzheimer's Disease, with Vascular Dementia (12%) and Mixed Dementia (12%) being the next 2 most common diagnoses.
- 48% of participants thought that, at the present time, their family member was in the middle stage of dementia, 28% thought that they were in the early stage, and 24% thought that they were in the late stage.
- 56% of participants indicated that, at the present time, their family member was living with the family, 32% were residing in a long term care facility, and 12% were residing in an assisted living facility.
- 67% of participants indicated that their family member was a spouse, and 33% a parent.
- Study participants indicated that they have been providing care for their family member due to dementia from 2 – 12 years.

Impact of the "Coping with Transitions" Education Series

- A *positive trend* was observed on the physical health scores as well as the mental health scores of the SF-12 among study participants from T1 to T2:
    - The mean score on physical health increased from 47.48 (SD=11.51) at T1 to 48.98 (SD=7.93) at T2.

  - The mean score on mental health increased from 42.45 (SD=11.08) at T1 to 44.90 (SD=8.63) at T2.
- A *positive trend* was observed on depression scores of the CESD among study participants from T1 (pre-assessment) to T2 (post-assessment):
  - The mean scores on depressive symptoms dropped from 9.00 (SD=3.29) in T1 to 8.86 (SD=3.09) in T2.
- A *positive trend* was observed on the subjective level of distress scores as well as the subjective health status scores of the CASQ among study participants from T1 to T2, but no difference was observed on the CASQ caregiver distress symptoms scores:
  - The mean scores on subjective level of distress dropped from 5.28 (SD=2.49) at T1 to 4.88 (SD=2.28) at T2.
  - The mean scores on subjective health status dropped from 4.77 (SD=2.39) at T1 to 4.31 (SD=2.60) at T2.
  - The mean scores on distress symptoms remained at 7 (SD=2.49/3.84) at T1 and T2.
- A *positive trend* was observed on the perceived social support scores on all subscales of the MSPSS among study participants from T1 to T2:
  - The mean scores on perceived social support from “significant others” increased from 15.38 (SD=3.62) at T1 to 18.85 (SD=4.20) at T2.
  - The mean scores on perceived social support from “family” increased from 14.33 (SD=3.60) at T1 to 14.38 (SD=4.45) at T2.
  - The mean scores on perceived social support from “friends” increased from 14.87 (SD=3.55) at T1 to 15.00 (SD=3.29) at T2.
  - The overall means scores on perceived social support increased from 43.84 (SD=8.15) at T1 to 45.26 (SD=11.22) at T2.
- A *positive trend* was observed on the subjective well-being scores of the WHO5 among study participants from T1 to T2:
  - The mean score on subjective well-being increased from 14.60 (SD3.94) at T1 to 15.32 (SD=4.87) at T2.
- A *positive trend* was observed on the satisfaction with life scores of the LSL among study participants from T1 to T2:
  - The mean score on satisfaction with life increased from 21.52 (SD=6.84) at T1 to 23.08 (SD=6.10) at T2.
- A *statistically significant positive change* was observed on all spirituality health subscales of the BMSWBI-S among study participants from T1 to T2 (Figure 1 & 2):
  - The mean score on subjective tranquility increased from 21.50 (SD=5.04) at T1 to

24.33 (SD=5.85) at T2 [t = -2.75, df = 23, p < .01].

- The mean score on subjective disorientation (inverted scored) increased from 25.15 (SD=6.04) at T1 to 27.15 (SD=6.64) at T2 [t = -2.19, df = 23, p < .05].
- The mean score on subjective resilience increased from 16.22 (SD=2.34) at T1 to 17.63 (SD=2.69) at T2 [t = -3.15, df = 26, p < .01].
- The overall mean score on subjective spirituality increased from 62.48 (SD=10.22) at T1 to 69.04 (SD=12.87) at T2 [t = -3.31, df = 22, p < .01].

Figure 1. Differences between caregivers' subscale scores on the Body-Mind-Spirit Well-Being Inventory before and after attending the Education Series

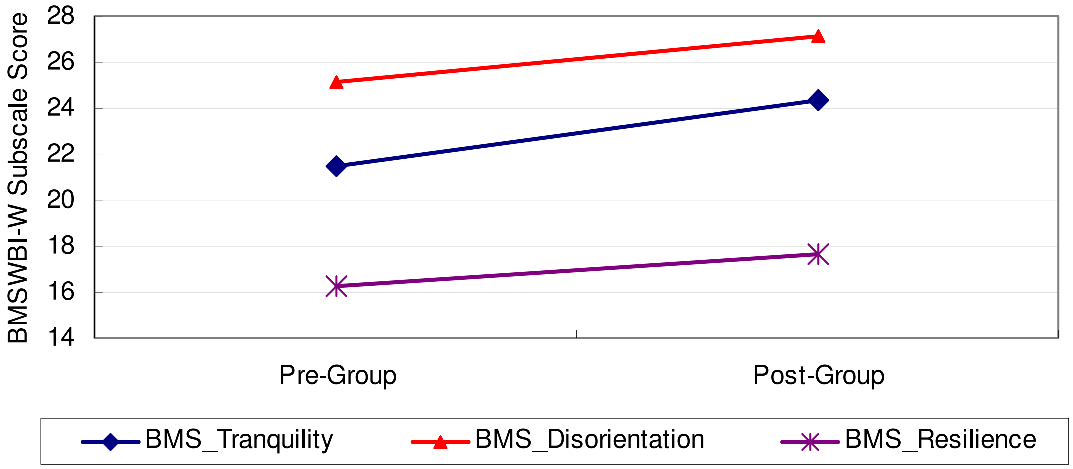
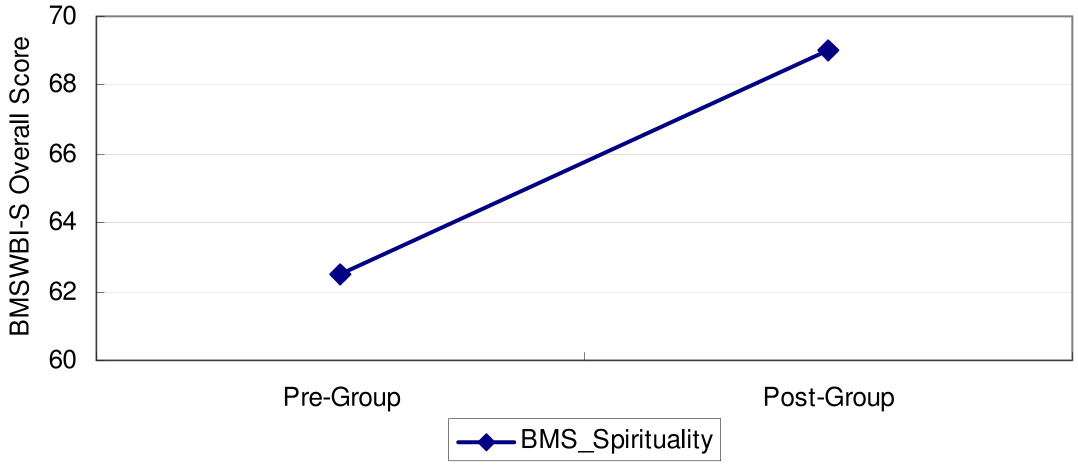


Figure 2. Differences between caregivers' overall scores on the Body-Mind-Spirit Well-Being Inventory before and after attending the Education Series



Evaluation of the "Coping with Transitions" Education Series

- 93% of participants felt that they learned useful information about the issues of grief and loss of the dementia journey through the education series.
- 93% of participants felt that the education series had helped them to better understand their feelings and reactions to all of the losses of the dementia journey.
- 89% of participants felt that the education series had provided them with some strategies and tools for their own self-care.
- 89% of participants felt that the education series had helped them to identify their warning signs of imbalance, stress, overload and burnout.
- 89% of participants felt that the education series had helped them to identify useful strategies that they can use to manage their energy through the caregiving marathon.
- 85% of participants felt that the education series had provided them with useful printed materials that they are likely to refer to again.
- 93% of participants felt that they have benefited greatly from participating in the education series:
    - "This series should be made available to all caregivers as soon as the diagnosis has been given. I have felt so strengthened by this group and I feel so fortunate to have been a part of this."
    - "It was an empowering and positive experience; it was life-changing."
- 93% of participants indicated that they would highly recommend the education series to other caregivers in the dementia journey.
    - "I would highly recommend this series to anyone who is a caregiver for someone with dementia regardless of the stage of the disease."
    - "It is a terrific program that I have already recommended to others. This is a marvelous resource for people caring for a family member with dementia."

The Effective Working Mechanisms of the "Coping with Transitions" Education Series

- When asked to describe in more detail what made the education series useful to them, most participants commented on the level of care and professional competence of the group counsellor/facilitator:
    - "I came looking for assistance, support and tools to assist me in coping with what, in many ways at the time, looked like a black hole into the future. The facilitator, participants and material all have provided me with strategies for coping and managing in a more accepting and positive manner."
    - "The counsellor is excellent at moderating the group and facilitating all members to

    share. I learned about stress indicators in myself that I need to pay more attention to".
    - "The counsellor is a gifted facilitator who is very inclusive and non-judgmental."
- The information/notes and relaxation exercises were identified to be useful to most participants:
    - "Information was given in manageable bites; Information helped to normalize and affirm my caregiving experience."
    - "I have a clearer understanding of the journey. The use of the relaxation exercise, the bouncing back and forth among the emotion and 'grief bursts' really helped me to restore balance and resilience."
- A safe and supportive group environment and peer learning were also identified to be useful to most participants:
    - "The process of exchanging ideas with others and exploring feelings with others helps me to accept my own grief. I am only alone when I choose to be. I can always reach out for help if I am willing. It begins with me."
    - "Interacting with other caregivers was extremely beneficial in providing me with an understanding and appreciation of the issues and challenges experienced in the marathon of caring for those suffering from brain disease."
- Lastly, some participants suggested that the education series could be improved with the inclusion of more activities such as meditation, relaxation exercises with music and poetry, and more time for discussion and group dialogue.

DISCUSSION

As demonstrated by the results from the various evaluation surveys and efficacy study, the First Link Dementia Network and the Dementia Transition Project were successes. First Link was designed to link newly diagnosed individuals with dementia and their families to a continuum of care that includes education, health services and support throughout the course of the disease. Within the first ten months of operation, more then 120 referrals were received by the First Link Coordinator from physicians and health care agencies. Linkages between physicians, community service providers, the Alzheimer Society of B.C. as well as the Vancouver Island Health Authority were strengthened through the collaborative work in developing a more effective referral system that includes a platform for information sharing via the First Link Bulletin. In terms of the Dementia Transition Project, it successfully designed and implemented an innovative education series that focused on the experiences of loss and grief of family caregivers, filling an identified gap in support and education services currently provided by the Alzheimer Society of B.C., other community agencies and formal health care system services.

Results from the First Link evaluation survey indicate that the program has competently helped individuals with dementia and their families in a number of ways including: learning more about dementia by receiving formal information about the disease and its related issues through Alzheimer Society publications sent by First Link; linking families to an wide array of services and programs rendered by the Alzheimer Society of B.C. such as education series and support groups; connecting families to other community resources such as residential care and adult day program; and providing families with a crucial point of contact in time of crises. First Link is also effective in reaching families and connecting them to support and services early on in their journey as over 50% of clients were diagnosed in 2008. Moreover, evaluation of the quality of service provided by First Link further reveals that the majority of families benefitted from their participation in the program, felt reassured that they can contact First Link for information and support, and would recommend First Link to other families facing dementia.

These accomplishments are even more significant given the fact that most affected families in B.C. know little about the disease as well as the programs and services that are available. Prior to joining First Link, nearly 70% of families had not received any formal information about dementia and nearly 80% of families indicated that they were not aware of available community services. The lack of knowledge and/or access to information and education among families affected by dementia further pinpoints the pivotal role that First Link plays in filling the critical gap in the formal integration, collaboration, and communication across settings, between health care providers, and across health authorities in the provision of dementia care in B.C.

The First link program also has benefits for health professionals, family physicians and other community agency staffs. Results from the Referring Agency evaluation survey revealed a roughly 30% increase in the number of referrals made by physicians and health professionals since the introduction of First Link. The majority of physicians and health professionals reported no obstacles in making use of the First Link referral service, they have formed a stronger relationship with the Alzheimer Society while at the same time have become more aware of services that are available in the community as a result of the First Link program. 100% of survey respondents reported that the First Link program has benefitted their practice; they also believed that their clients have greatly benefited from participating in First Link through receiving support, education/information and linkage to community services.

With regards to the Dementia Transition Project, results from the efficacy study on the “Coping with Transitions” education series indicate the project’s success in addressing current needs of family caregivers. Through completing the 6-part learning series, a clear trend of improvement among participants’ overall well-being is observed, including: improvement in subjective physical health and mental health; reduction in depressive symptoms; lower levels of perceived caregiver distress; greater levels of perceived social support; and greater satisfaction with life. Participants have also displayed statistically significant improvements in their overall spiritual health with the completion of the 6-part learning series; in particular, their level of disorientation was reduced while their feelings of tranquility and resilience have amplified. All of these findings reflect the education series’ effectiveness in achieving its goals to support family caregivers’ feelings of loss and grief, their fears and concerns and to help them prepare for the future. Lastly, subjective quality evaluations further reveal that nearly all clients felt they have benefited from the education series, learned ways to identify and reduce their sense of stress and burnout, obtained useful strategies and tools for self-care, and found refuge and support through a competently facilitated group environment.

The rapidly increasing prevalence rate of dementia coupled with the progressive nature of the disease mirror the fact that more and more families will require greater care needs in support, services and education. The overall results from this evaluation clearly demonstrate that families in Victoria, B.C. now have a point of contact and support through the First Link program, while caregivers will have the opportunity to obtain loss and grief related education and support that was previously missing in the service provision. Comments from participants of the “Coping with Transitions” education series neatly encapsulate the experience: “The facilitator, participants and material all have provided me with strategies for coping and managing in a more accepting and positive manner…It was an empowering and positive experience; it was life-changing…It is a terrific program that I have already recommended to others. This is a marvelous resource for people caring for a family member with dementia”.

In sum, the First Link Dementia Network & the Dementia Transition Project have demonstrated vast potential and ability to connect with and deliver community-based learning, support and services to the increasing number of families affected by dementia. This quality assurance evaluative study has found many examples of good practice as all evidence indicates that the two projects are user-friendly. Clients overwhelmingly welcome the introduction of the First Link model; whilst community stakeholders are equally excited with the new possibility and efficiency of its design. Such positive evaluation results from families, physicians and health care professionals reflect not only on the First Link program and the Dementia Transition Project, but also on the work of the Alzheimer Society of B.C. and its partnership with the Vancouver Island Health Authority.

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APPENDIX I

First Link Evaluation Survey

Alzheimer Society of B.C.
First Link - Quality Assurance Evaluation Study

Verbal Consent From

First Link is an initiative developed by the Alzheimer Society of B.C. Its goal is to create a direct referral system that proactively connects individuals newly diagnosed with dementia and their families to support, education and services that are available in the community.

In order to facilitate evidence-based practice while at the same time ensuring the quality of services provided by First Link, we request your participation in the First Link – Quality Assurance Evaluation Study. This will involve responding to a series of questions that focus on your personal experience of dementia as well as your evaluation of First Link services on your initial contact with First Link and during your 3-month follow up call. These questions will take no more than 10 minutes to complete. Your participation in this study can provide us with valuable information for developing and refining a more effective referral service for people with dementia and their families. All personal information and responses you provide will be treated as strictly confidential, and no reference will be made in any oral or written reports that could link your participation to this study. Moreover, your participation is strictly voluntary and you can choose to stop at any time without any negative consequences.

Do you have any questions regarding the First Link – Quality Assurance Evaluation Study?

Having understood the content described to you, do you agree to participate in the First Link – Quality Assurance Evaluation Study?

☐ Agree
☐ Refuse: ____

Respondent Identification #:								
Questionnaire Completion Date:								
	D	D	M	M	Y	E	A	R

Staff Initial: ______________________

First Link – Quality Assurance Evaluation Study

Questionnaire I (Pre-Test)
Intake Assessment

{Respondent is: ☐ 1) person with dementia ☐ 2) care partner}

{Person with dementia was diagnosed: ______/______ (month/year)}

1. Prior to being referred to First Link, had you heard of the Alzheimer Society?
☐ 1) Yes ☐ 2) No **(Skip to question 5)**

2. Did you know the type of programs and services that the Alzheimer Society offers?
☐ 1) Yes ☐ 2) No **(Skip to Question 5)**

3. *If so, have you participated in any of the following Alzheimer Society programs?*
☐ 1) Support group – Early Stage ☐ 2) Support group – Caregiver
☐ 3) Education – Dementia Series ☐ 4) Education – Shaping the Journey
☐ 5) Individual support ☐ 6) Information/Library
☐ 7) Newsletters ☐ 8) Safely Home / BC Photo Registry
☐ 9) *Coping with Transitions* ☐ 10) None **(Go to Question 4)**

4. *The reason why you have not participated in any Alzheimer Society programs is*
☐ 1) Newly diagnosed ☐ 2) Lack of transportation
☐ 3) Times of program not convenient ☐ 4) Unable to leave my family member alone
☐ 5) Programs not of interest to me / do not meet my needs
☐ 6) Other ____
☐ 7) Unable to ask question

5. Prior to your referral to First Link, were you aware of other services in the community that can help you cope with dementia?
☐ 1) Yes ☐ 2) No **(Skip to Question 8)**

6. If so, have you participated in any of those services?
☐ 1) Memory PLUS ☐ 2) Family Caregivers Network
☐ 3) Hillside Wellness Centre ☐ 4) Adult Day Program
☐ 4) Home Support ☐ 5) Respite
☐ 6) Other_________________________ ☐ 7) None **(Go to question 7)**

7. The reason why you have not participated in other community programs is:
☐ 1) Newly diagnosed ☐ 2) Lack of transportation
☐ 3) Times of program not convenient ☐ 4) Unable to leave my family member alone
☐ 5) Programs not of interest to me/ do not meet my needs
☐ 6) Other ____
☐ 7) Unable to ask question

8. Prior to First Link, Have you received any formal information about dementia and its related issues (i.e.

booklet, handout)?

☐ Yes ☐ No

9. At this time, are you interested in participating in any Alzheimer Society programs?

☐ 1) Yes ☐ 2) No **(Skip to Question 11)**

10. If so, which programs?

☐ 1) Support group – Early Stage ☐ 2) Support group – Caregiver
☐ 3) Education – Dementia Series ☐ 4) Education – Shaping the Journey
☐ 5) Individual support ☐ 6) Information/Library
☐ 7) Newsletters ☐ 8) Safely Home / BC Photo Registry
☐ 9) *Coping with Transitions*

11. The reason why you are not interested in participating in any Alzheimer Society programs at this time:

☐ 1) Not yet needed ☐ 2) Lack of transportation
☐ 3) Times of program not convenient ☐ 4) Unable to leave my family member alone
☐ 5) Programs not of interest to me / do not meet my needs
☐ 6) Other ____________________
☐ 7) Unable to ask question

12. At this time, are you interested in participating in any other services in the community?

☐ 1) Yes ☐ 2) No **(Skip to Question 14)**

13. If so, which services?

☐ 1) Memory PLUS ☐ 2) Family Caregivers Network
☐ 3) Hillside Wellness Centre ☐ 4) Adult Day Program
☐ 4) Home Support ☐ 5) Respite
☐ 6) Other____________________

14. The reason why you are not interested in participating in other community programs is:

☐ 1) Not yet needed ☐ 2) Lack of transportation
☐ 3) Times of program not convenient ☐ 4) Unable to leave my family member alone
☐ 5) Programs not of interest to me / do not meet my needs
☐ 6) Other ____________________
☐ 7) Unable to ask question

15. Would you feel comfortable having the First Link Coordinator call you in approximately 3 months?

☐ Yes ☐ No

Other Comments:

____
____
____

-END-

First Link – Quality Assurance Evaluation Study

Questionnaire II (Post-Test)
Follow-up Assessment

Respondent Identification #:								
Questionnaire Completion Date:								
	D	D	M	M	Y	E	A	R

1. Over the past 3 months, has First Link connected you with any Alzheimer Society Programs?
☐ 1) Yes ☐ 2) No **(Skip to Question 3)**

2. If so, which of the following Alzheimer Society programs have you participated in?
☐ 1) Support group – Early Stage
☐ 3) Education – Dementia Series
☐ 5) Individual support
☐ 7) Newsletters
☐ 9) *Coping with Transitions*
☐ 2) Support group – Caregiver
☐ 4) Education – Shaping the Journey
☐ 6) Information/Library
☐ 8) Safely Home / BC Photo Registry

3. Over the past 3 months, has First Link helped you to link to other dementia-related services that are available in the community?
☐ 1) Yes ☐ 2) No **(Skip to Question 5)**

4. If so, which of the following community services have you participated in?
☐ 1) Memory PLUS
☐ 3) Hillside Wellness Centre
☐ 4) Home Support
☐ 6) Other____
☐ 2) Family Caregivers Network
☐ 4) Adult Day Program
☐ 5) Respite

5. *Over the past 3 months, have you received any formal information about dementia and its related issues from First Link (i.e. booklet, handout)?*
☐ Yes ☐ No

6. *If you have a concern or question about Alzheimer disease/dementia, caregiving, etc. who do you usually contact for assistance?*
☐ 1) No One ☐ 2) Family / friends ☐ 3) First Link ☐ 4) Family Physician
☐ 5) Case Manager ☐ 6) Alzheimer Society ☐ 7) Other____________________

7. *Over the past 3 months, have you contacted First Link? (client-initiated call)*
☐ Yes ☐ No

On a scale of 1 to 5, 1 being “Not at all Important” to 5 being “Extremely Important”, how would you rate the following:

8. Having First Link call me, rather than me having to make the call:

☐ 1)	☐ 2)	☐ 3)	☐ 4)	☐ 5)
Not at all Important	Somewhat Unimportant	Neutral	Somewhat Important	Extremely Important

9. Knowing that I can call First Link for information, programs and services that can help me to cope with my/my family member's dementia

☐ 1)	☐ 2)	☐ 3)	☐ 4)	☐ 5)
Not at all Important	Somewhat Unimportant	Neutral	Somewhat Important	Extremely Important

On a scale of 1 to 5, 1 being "Totally Disagree" to 5 being "Totally Agree", how would you rate the following:

10. I know more about dementia-related services and programs available in the community.

☐ 1)	☐ 2)	☐ 3)	☐ 4)	☐ 5)
Strongly Disagree	Somewhat Disagree	Neutral / Don't Know	Somewhat Agree	Strongly Agree

11. The First Link bulletin provides me with information about programs available in the community.

☐ 1)	☐ 2)	☐ 3)	☐ 4)	☐ 5)
Strongly Disagree	Somewhat Disagree	Neutral / Don't Know	Somewhat Agree	Strongly Agree

12. *I know more about Alzheimer Disease/dementia through the information package I received through First Link*.

☐ 1)	☐ 2)	☐ 3)	☐ 4)	☐ 5)
Strongly Disagree	Somewhat Disagree	Neutral / Don't Know	Somewhat Agree	Strongly Agree

13. In general, I have benefited from participating in the First Link program.

☐ 1)	☐ 2)	☐ 3)	☐ 4)	☐ 5)
Strongly Disagree	Somewhat Disagree	Neutral / Don't Know	Somewhat Agree	Strongly Agree

14. I would recommend First Link to people with dementia and their family members.

☐ 1)	☐ 2)	☐ 3)	☐ 4)	☐ 5)
Strongly Disagree	Somewhat Disagree	Neutral / Don't Know	Somewhat Agree	Strongly Agree

Other Comments:

-END-

Appendix II

Referring Agency Evaluation Survey

First Link – Quality Assurance Evaluation Study
Referring Physician / Agency Survey

1. *How did you first hear about First Link?*
☐ presentation/meeting ☐ from a colleague ☐ referral package mailed / dropped off
☐ First Link e-bulletin ☐ Other: ______________________________

2. *Before the introduction of the First Link program, approximately how many clients/patients per month did you refer to the Alzheimer Society?*
☐ None ☐ 1-3 ☐ 4-7 ☐ more than 7

3. *Since the introduction of the First Link program, approximately how many clients/patients per month have you referred to First Link?*
☐ None ☐ 1-3 ☐ 4-7 ☐ more than 7

4. *Have you encountered any obstacles to making a referral to First Link?*
☐ Yes ☐ No

If yes, please indicate obstacle:
☐ Insufficient information about First Link ☐ Lack of time ☐ Lack of referral form
☐ Other: ______________________________

5. *Approximately how many clients declined a referral to First Link?*
☐ None ☐ 1-3 ☐ 4-7 ☐ more than 7

What reason(s) did they give?
____

6. *What was your primary reason for referring clients to First Link?*
☐ information ☐ education ☐ support ☐ link to community services
☐ other, please specify ______________________________

On a scale of 1 to 5, 1 being "Strongly Disagree" to 5 being "Strongly Agree" how would you rate the following:

7. *Making a referral to First Link was easy and simple.*

☐ 1)	☐ 2)	☐ 3)	☐ 4)	☐ 5)
Strongly Disagree	Somewhat Disagree	Neutral / Don't Know	Somewhat Agree	Strongly Agree

8. *The referral package provided sufficient information about First Link.*

☐ 1)	☐ 2)	☐ 3)	☐ 4)	☐ 5)
Strongly Disagree	Somewhat Disagree	Neutral / Don't Know	Somewhat Agree	Strongly Agree

9. *I believe that my clients/patients have benefited from participating in First Link.*

☐ 1)	☐ 2)	☐ 3)	☐ 4)	☐ 5)
Strongly Disagree	Somewhat Disagree	Neutral / Don't Know	Somewhat Agree	Strongly Agree

How?

10. *I believe that the First Link program has benefited my practice/service.*

☐ 1)	☐ 2)	☐ 3)	☐ 4)	☐ 5)
Strongly Disagree	Somewhat Disagree	Neutral / Don't Know	Somewhat Agree	Strongly Agree

How?

11. *I am more aware of the services offered by the Alzheimer Society as a result of First Link.*

☐ 1)	☐ 2)	☐ 3)	☐ 4)	☐ 5)
Strongly Disagree	Somewhat Disagree	Neutral / Don't Know	Somewhat Agree	Strongly Agree

12. *Through the First Link e-bulletin, I am more aware of other dementia-related community services as a result of First Link.*

☐ 1)	☐ 2)	☐ 3)	☐ 4)	☐ 5)
Strongly Disagree	Somewhat Disagree	Neutral / Don't Know	Somewhat Agree	Strongly Agree

13. I would recommend First Link to other health professionals.

☐ 1)	☐ 2)	☐ 3)	☐ 4)	☐ 5)
Strongly Disagree	Somewhat Disagree	Neutral / Don't Know	Somewhat Agree	Strongly Agree

14. Other Comments:

Please indicate:
15. I am a …

☐ Family Physician ☐ Specialist ☐ Case Manager ☐ Social Worker

☐ Community agency staff ☐ Other: ____________________

16. Are you connected to SARIN? ☐ Yes ☐ No

-END-

Appendix III

Dementia Transition Project Efficacy Evaluation Study

Alzheimer Society
BRITISH COLUMBIA

A Quality Assurance Evaluation Study on

Coping with Transitions in Dementia Caregiving: Dimensions of Loss & Grief

Caregivers' Survey

Pre-Group Questionnaire

2008-2009

Respondent Identification #:

Questionnaire Completion Date:

D D M M Y E A R

Handled By:

Section A. Health Questionnaire Short Form (SF-12)

A1. In general, would you say your health is:

☐ 1 Excellent ☐ 2 Very Good ☐ 3 Good ☐ 4 Fair ☐ 5 Poor

The following items are about activities you might do during a typical day.

Does your health now limit you in these activities? If so, how much?

(1 = Yes, Limited a lot 2 = Yes, Limited a little 3 = No limitations)

A2.	**Moderate activities**, such as moving tables, pushing a vacuum cleaner, exercises, etc.	☐ 1	☐ 2	☐ 3
A3.	Climbing **several** flights of stairs	☐ 1	☐ 2	☐ 3

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

A4.	**Accomplished less** than you would like	☐ 1 Yes	☐ 2 No
A5.	Were limited in the **kind** of work or other activities	☐ 1 Yes	☐ 2 No

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed, anxious or irritable)?

A6.	**Accomplished less** than you would like	☐ 1 Yes	☐ 2 No
A7.	Didn't do work or other activities as **carefully** as usual	☐ 1 Yes	☐ 2 No

A8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

☐ 1 Not at all ☐ 2 A little bit ☐ 3 Moderately ☐ 4 Quite a Bit ☐ 5 Extremely

During the past 4 weeks:		All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
A9.	Have you felt calm and peaceful?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
A10.	Did you have a lot of energy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
A11.	Have you felt downhearted and blue?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

A12. During the past 4 weeks, how much of the time have your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

☐ 1 All of the time ☐ 2 Most of the time ☐ 3 Sometimes ☐ 4 A little of the Time ☐ 5 None of the time

Section B. Center for Epidemiologic Studies–Depression Scale (Short Form 5)				
Over the Past Week…	(Less than 1 Day) Rarely	(1-2 Days) Sometimes	(3-4 Days) Occasionally	(5-7 Days) Mostly
B1. I felt depressed.	☐ 1	☐ 2	☐ 3	☐ 4
B2. My sleep was restless.	☐ 1	☐ 2	☐ 3	☐ 4
B3. I felt lonely.	☐ 1	☐ 2	☐ 3	☐ 4
B4. I had crying spells.	☐ 1	☐ 2	☐ 3	☐ 4
B5. I could not get "going".	☐ 1	☐ 2	☐ 3	☐ 4

Section C. AMA Caregiver Stress Self-Assessment		
Over the Past Week, I have…	Yes	No
C1. Had trouble keeping my mind on what I was doing.	☐ 1	☐ 2
C2. Felt that I couldn’t leave my family member alone.	☐ 1	☐ 2
C3. Had difficulty making decisions.	☐ 1	☐ 2
C4. Felt completely overwhelmed.	☐ 1	☐ 2
C5. Felt useful and needed.	☐ 1	☐ 2
C6. Felt lonely.	☐ 1	☐ 2
C7. Been upset that my family member has changed so much from his/her former self.	☐ 1	☐ 2
C8. Felt a loss of privacy and/or personal time.	☐ 1	☐ 2
C9. Been edgy or irritable.	☐ 1	☐ 2
C10. Had my sleep disturbed because of caring for my loved one.	☐ 1	☐ 2
C11. Had crying spell(s).	☐ 1	☐ 2
C12. Felt strained between work and family responsibilities.	☐ 1	☐ 2
C13. Had back pain.	☐ 1	☐ 2
C14. Felt ill (headaches, stomach problems or common cold).	☐ 1	☐ 2
C15. Been satisfied with the support my family has given me.	☐ 1	☐ 2
C16. Found my family member’s dementia to be a barrier to my self-care.	☐ 1	☐ 2
C17. On a scale of 1 to 10, with 1 being “not stressful” to 10 being “extremely stressful”, Please rate your current level of stress:	Rating: ________ (1-10)	
C18. On a scale of 1 to 10, with 1 being “very healthy” to 10 being “ill” please rate your current level of health.	Rating: ________ (1-10)	

Section D. Perceived Social Support Scale					
Below are statements with which you may agree or disagree. Please indicate your agreement with each statement by circling the number corresponding to the best answer. *(1 = Strongly Disagree, 5 = Strongly Agree)*	Strongly Disagree		Neutral		Strongly Agree
D1. There is a special person who is around when I am in need.	1	2	3	4	5
D2. There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5
D3. My family really tries to help me.	1	2	3	4	5
D4. I get the emotional help and support I need from my family.	1	2	3	4	5
D5. I have a special person who is a real source of comfort to me.	1	2	3	4	5
D6. My friends really try to help me.	1	2	3	4	5
D7. I can count on my friends when things go wrong.	1	2	3	4	5
D8. I can talk about my problems with my family.	1	2	3	4	5
D9. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5
D10. There is a special person in my life who cares about my feelings.	1	2	3	4	5
D11. My family is willing to help me make decisions.	1	2	3	4	5
D12. I can talk about my problems with my friends.	1	2	3	4	5

Section E. WHO Well-being (Five) index					
Over the past week…	At no time	Some of the time	More than half the time	Most of the time	All the time
E1. I have felt cheerful and in good spirits.	1	2	3	4	5
E2. I have felt calm and relaxed.	1	2	3	4	5
E3. I have felt active and vigorous.	1	2	3	4	5
E4. I woke up feeling fresh and rested.	1	2	3	4	5
E5. My daily life has been filled with things that interest me.	1	2	3	4	5

Section F. BMSWBI Spirituality Subscale							
Please circle the numbers that best fit how you react to the following thoughts, feelings, or behaviors. *(1 = Strongly Disagree, 7 = Strongly Agree)*	Strongly Disagree			Neutral			Strongly Agree
F1. I have lost direction in life.	1	2	3	4	5	6	7
F2. I don't know how to love myself.	1	2	3	4	5	6	7

F3. I don't understand why predicaments/challenges come to me.	1	2	3	4	5	6	7
F4. Facing a predicament/challenge is a learning opportunity to me.	1	2	3	4	5	6	7
F5. I am grateful to those around me for the things that they do for me.	1	2	3	4	5	6	7
F6. I blame heaven (or the world, the universe) for being unfair to me.	1	2	3	4	5	6	7
F7. Predicaments/challenges can make me stronger.	1	2	3	4	5	6	7
F8. I lack the vitality of life.	1	2	3	4	5	6	7
F9. I can be content with whatever comes.	1	2	3	4	5	6	7
F10. I can face life with a moderate state of mind.	1	2	3	4	5	6	7
F11. I feel calmness and harmony deep in my heart.	1	2	3	4	5	6	7
F12. I can take something on or let go of it.	1	2	3	4	5	6	7
F13. I can deal with difficulties methodically.	1	2	3	4	5	6	7

Section G. Satisfaction with Life Scale							
Below are 5 statements with which you may agree or disagree. Please indicate your response to each statement by circling the number corresponding to the best answer. *(1 = Strongly Disagree, 7 = Strongly Agree)*	Strongly Disagree			Neutral			Strongly Agree
G1. In most ways, my life is close to my ideal	1	2	3	4	5	6	7
G2. The conditions of my life are excellent.	1	2	3	4	5	6	7
G3. I am satisfied with my life.	1	2	3	4	5	6	7
G4. So far, I have gotten the important things I want in life.	1	2	3	4	5	6	7
G5. If I could life my life over, I would change almost nothing.	1	2	3	4	5	6	7

Section H-1. Background Information					
Your Age: ____________________			*Gender:* ☐ 1. Male ☐ 2. Female		
What is the highest level of education you have completed?					
☐ 1. Less than grade 12	☐ 2. Graduated Secondary School	☐ 3. Partial College or University	☐ 4. College certificate or diploma	☐ 5. University degree	☐ 6. Post Graduate degree
Employment Status:					
☐ 1. Retired	☐ 2. Homemaker	☐ 3. Student	☐ 4. P/T Employed	☐ 5. F/T Employed	☐ 6. Unemployed
Number of Children:			*Age range of children if under 19 years:*		
☐ None	☐ 1	☐ 2 and above	Youngest _____	Eldest _____	

What month and year was your family member diagnosed?

Month: _____________ Year: _____________

Age of the family member you are caring for: _______

Gender of your family member: ☐ 1. Male ☐ 2. Female

My family member was diagnosed with:

☐ 1. Alzheimer's disease	☐ 2. Vascular dementia	☐ 3. Mixed dementia (Vascular & AD)
☐ 4. Lewy-body dementia	☐ 5. Frontotemporal dementia	☐ 6. Not sure

I think that my family member is in the:

☐ 1. early ☐ 2. middle ☐ 3. late - stage of dementia

My family member resides:

☐ 1. alone ☐ 2. w/ family ☐ 3. Assisted Living facility ☐ 4. long term care facility

The family member I am caring for is my

☐ 1. spouse ☐ 2. parent ☐ 3. sibling ☐ 4. other: ______________________

How long have you been providing care for your family member due to their dementia?

_______________ months/years

How did you hear about this Coping with Transitions group?

☐ 1. Doctor or Specialist	☐ 2. Other Health Care Provider	☐ 3. First Link Coordinator
☐ 4. Alzheimer Society support staff or volunteer	☐ 5. At a support group	☐ 6. At an education program

☐ 7. Other: ___________________

I have participated in/utilized the following Alzheimer Society programs/services:

☐ 1. One-to-one consultations with staff or volunteers		☐ 2. Caregiver Support Group
☐ 3. Education program	☐ 4. resource library / information materials	☐ 5. Other: __________________________

H17. *My family member has participated in the Early Stage Dementia support group:* ☐ Yes ☐ No

H18*. If you have not participated in any Alzheimer Society programs/services, please indicate reasons why*

☐ 1. Don't know about the programs	☐ 2. Lack of Transportation
☐ 3. Times of programs not convenient	☐ 4. Unable to leave my family member alone
☐ 5. Programs not of interest to me/ do not meet my needs	☐ 6. Other: ______________________________________

- End • Thank You -

Alzheimer *Society*
BRITISH COLUMBIA

A Quality Assurance Evaluation Study on

Coping with Transitions in Dementia Caregiving: Dimensions of Loss & Grief

Caregivers' Survey

Post-Group Questionnaire

2008-2009

Respondent Identification #:

Questionnaire Completion Date:

D D M M Y E A R

Handled By:

Section A. Health Questionnaire Short Form (SF-12)

A13. In general, would you say your health is:

☐ 1 Excellent ☐ 2 Very Good ☐ 3 Good ☐ 4 Fair ☐ 5 Poor

The following items are about activities you might do during a typical day.

Does your health now limit you in these activities? If so, how much?

(1 = Yes, Limited a lot 2 = Yes, Limited a little 3 = No limitations)

A14. **Moderate activities**, such as moving tables, pushing a vacuum cleaner, exercises, etc.	☐ 1	☐ 2	☐ 3
A15. Climbing **several** flights of stairs	☐ 1	☐ 2	☐ 3

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

A16. **Accomplished less** than you would like	☐ 1 Yes	☐ 2 No
A17. Were limited in the **kind** of work or other activities	☐ 1 Yes	☐ 2 No

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed, anxious or irritable)?

A18. **Accomplished less** than you would like	☐ 1 Yes	☐ 2 No
A19. Didn't do work or other activities as **carefully** as usual	☐ 1 Yes	☐ 2 No

A20. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

☐ 1 Not at all ☐ 2 A little bit ☐ 3 Moderately ☐ 4 Quite a Bit ☐ 5 Extremely

During the past 4 weeks:	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
A21. Have you felt calm and peaceful?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
A22. Did you have a lot of energy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
A23. Have you felt downhearted and blue?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

A24. During the past 4 weeks, how much of the time have your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

☐ 1 All of the time ☐ 2 Most of the time ☐ 3 Sometimes ☐ 4 A little of the Time ☐ 5 None of the time

Section B. Center for Epidemiologic Studies–Depression Scale (Short Form 5)				
Over the Past Week…	(Less than 1 Day) Rarely	(1-2 Days) Sometimes	(3-4 Days) Occasionally	(5-7 Days) Mostly
B6. I felt depressed.	☐ 1	☐ 2	☐ 3	☐ 4
B7. My sleep was restless.	☐ 1	☐ 2	☐ 3	☐ 4
B8. I felt lonely.	☐ 1	☐ 2	☐ 3	☐ 4
B9. I had crying spells.	☐ 1	☐ 2	☐ 3	☐ 4
B10. I could not get "going".	☐ 1	☐ 2	☐ 3	☐ 4

Section C. AMA Caregiver Stress Self-Assessment		
Over the Past Week, I have…	Yes	No
C19. Had trouble keeping my mind on what I was doing.	☐ 1	☐ 2
C20. Felt that I couldn’t leave my family member alone.	☐ 1	☐ 2
C21. Had difficulty making decisions.	☐ 1	☐ 2
C22. Felt completely overwhelmed.	☐ 1	☐ 2
C23. Felt useful and needed.	☐ 1	☐ 2
C24. Felt lonely.	☐ 1	☐ 2
C25. Been upset that my family member has changed so much from his/her former self.	☐ 1	☐ 2
C26. Felt a loss of privacy and/or personal time.	☐ 1	☐ 2
C27. Been edgy or irritable.	☐ 1	☐ 2
C28. Had my sleep disturbed because of caring for my loved one.	☐ 1	☐ 2
C29. Had crying spell(s).	☐ 1	☐ 2
C30. Felt strained between work and family responsibilities.	☐ 1	☐ 2
C31. Had back pain.	☐ 1	☐ 2
C32. Felt ill (headaches, stomach problems or common cold).	☐ 1	☐ 2
C33. Been satisfied with the support my family has given me.	☐ 1	☐ 2
C34. Found my family member’s dementia to be a barrier to my self-care.	☐ 1	☐ 2
C35. On a scale of 1 to 10, with 1 being “not stressful” to 10 being “extremely stressful”, Please rate your current level of stress:	Rating: _______ (1-10)	
C36. On a scale of 1 to 10, with 1 being “very healthy” to 10 being “ill” please rate your current level of health.	Rating: _______ (1-10)	

Section D. Perceived Social Support Scale					
Below are statements with which you may agree or disagree. Please indicate your agreement with each statement by circling the number corresponding to the best answer. *(1 = Strongly Disagree, 5 = Strongly Agree)*	Strongly Disagree		Neutral		Strongly Agree
D13. There is a special person who is around when I am in need.	1	2	3	4	5
D14. There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5
D15. My family really tries to help me.	1	2	3	4	5
D16. I get the emotional help and support I need from my family.	1	2	3	4	5
D17. I have a special person who is a real source of comfort to me.	1	2	3	4	5
D18. My friends really try to help me.	1	2	3	4	5
D19. I can count on my friends when things go wrong.	1	2	3	4	5
D20. I can talk about my problems with my family.	1	2	3	4	5
D21. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5
D22. There is a special person in my life who cares about my feelings.	1	2	3	4	5
D23. My family is willing to help me make decisions.	1	2	3	4	5
D24. I can talk about my problems with my friends.	1	2	3	4	5

Section E. WHO Well-being (Five) index					
Over the past week…	At no time	Some of the time	More than half the time	Most of the time	All the time
E6. I have felt cheerful and in good spirits.	1	2	3	4	5
E7. I have felt calm and relaxed.	1	2	3	4	5
E8. I have felt active and vigorous.	1	2	3	4	5
E9. I woke up feeling fresh and rested.	1	2	3	4	5
E10. My daily life has been filled with things that interest me.	1	2	3	4	5

Section F. BMSWBI Spirituality Subscale							
Please circle the numbers that best fit how you react to the following thoughts, feelings, or behaviors. *(1 = Strongly Disagree, 7 = Strongly Agree)*	Strongly Disagree			Neutral			Strongly Agree
F14. I have lost direction in life.	1	2	3	4	5	6	7
F15. I don’t know how to love myself.	1	2	3	4	5	6	7

F16. I don't understand why predicaments/challenges come to me.	1	2	3	4	5	6	7
F17. Facing a predicament/challenge is a learning opportunity to me.	1	2	3	4	5	6	7
F18. I am grateful to those around me for the things that they do for me.	1	2	3	4	5	6	7
F19. I blame heaven (or the world, the universe) for being unfair to me.	1	2	3	4	5	6	7
F20. Predicaments/challenges can make me stronger.	1	2	3	4	5	6	7
F21. I lack the vitality of life.	1	2	3	4	5	6	7
F22. I can be content with whatever comes.	1	2	3	4	5	6	7
F23. I can face life with a moderate state of mind.	1	2	3	4	5	6	7
F24. I feel calmness and harmony deep in my heart.	1	2	3	4	5	6	7
F25. I can take something on or let go of it.	1	2	3	4	5	6	7
F26. I can deal with difficulties methodically.	1	2	3	4	5	6	7

Section G. Satisfaction with Life Scale

Below are 5 statements with which you may agree or disagree. Please indicate your response to each statement by circling the number corresponding to the best answer. *(1 = Strongly Disagree, 7 = Strongly Agree)*	Strongly Disagree			Neutral			Strongly Agree
G6. In most ways, my life is close to my ideal	1	2	3	4	5	6	7
G7. The conditions of my life are excellent.	1	2	3	4	5	6	7
G8. I am satisfied with my life.	1	2	3	4	5	6	7
G9. So far, I have gotten the important things I want in life.	1	2	3	4	5	6	7
G10. If I could life my life over, I would change almost nothing.	1	2	3	4	5	6	7

Section H-2. User Evaluation

(There are no right or wrong answers. Please answer according to your own feelings.)

What attracted you to attend this Education Series? How did you decide to attend?

____

____

____

You have learned useful information about the issues of Grief and Loss of the Dementia Journey through this Series.

☐ 1. Strongly Disagree ☐ 2. Disagree ☐ 3. Neutral ☐ 4. Agree ☐ 5. Strongly Agree

The Coping with Transitions Series has helped you to better understand your feelings and reactions to all of the losses of the dementia journey.

☐ 1. Strongly Disagree ☐ 2. Disagree ☐ 3. Neutral ☐ 4. Agree ☐ 5. Strongly Agree

The Coping with Transitions Series has provided you with some strategies and tools for your own self-care.

☐ 1. Strongly Disagree ☐ 2. Disagree ☐ 3. Neutral ☐ 4. Agree ☐ 5. Strongly Agree

The Coping with Transitions Series has helped you to identify your warning signs of imbalance/stress overload/burnout.

☐ 1. Strongly Disagree ☐ 2. Disagree ☐ 3. Neutral ☐ 4. Agree ☐ 5. Strongly Agree

The Coping with Transitions Series has helped you to identity some strategies that you can use to manage your energy through the "caregiving marathon".

☐ 1. Strongly Disagree ☐ 2. Disagree ☐ 3. Neutral ☐ 4. Agree ☐ 5. Strongly Agree

The Coping with Transitions Series has provided you with useful printed materials that you are likely to refer to again.

☐ 1. Strongly Disagree ☐ 2. Disagree ☐ 3. Neutral ☐ 4. Agree ☐ 5. Strongly Agree

***Overall, you have benefited greatly from participating in the Coping with Transitions Series*.**

☐ 1. Strongly Disagree ☐ 2. Disagree ☐ 3. Neutral ☐ 4. Agree ☐ 5. Strongly Agree

I would highly recommend the Coping with Transitions Series to other caregivers in the dementia journey.

☐ 1. Strongly Disagree ☐ 2. Disagree ☐ 3. Neutral ☐ 4. Agree ☐ 5. Strongly Agree

Having a light meal provided was important for me to be able to attend.

☐ 1. Strongly Disagree ☐ 2. Disagree ☐ 3. Neutral ☐ 4. Agree ☐ 5. Strongly Agree

Please describe in more detail ***what*** *made this education series useful to you?*
Please describe any changes you would recommend (e.g. pacing, more time or less time on a given topic, fewer sessions, additions, deletions):
Please provide any additional comments and suggestions for the Coping with Transitions Series:

- End • Thank You -