

**Gabriola Community Hospice Palliative Care  
Report on Working Group Activities and Findings of the Public  
Forum “*Understanding How Compassionate Communities Can  
Support Those Needing Palliative Care*”**

**October 14, 2018**

**Drafted by**

**Ms. Nancy Rowan and Dr. Vicky Scott**



## Executive summary

This report reflects the work of Palliative Care Working Group and the outcomes of the Public Forum on *“Understanding How Compassionate Communities Can Support Those Needing Palliative Care”*. The impetuses for this work arose out of a need identified at the 2018 Fall Forum of the Gabriola Health and Wellness Collaborative for support of the dying and their families on Gabriola. The Working Group goals are twofold. The first is to enhance patient/family access to an integrated and coordinated system of professional services including advanced training for physicians and professional staff in palliative care. The second is to initiate a process leading to the development of a Gabriola community-based hospice care program to meet practical, psychosocial and spiritual needs patients and their families. To meet the second goal, a public forum was held to contribute to the understanding of the need for personal and community development to support terminally ill patients and their families and to garner public input into the design and implementation of Gabriola based hospice care program. This report focuses on the development of community hospice care.

The outcomes of the forum resulted in four key themes to guide future planning for an integrated community hospice palliative care system for Gabriola.

1. Administration and Coordination
2. Information and Resources
3. Psychosocial Supports
4. Household and Family Supports

For each theme, community participants reported on a wealth of existing resources and identified gaps that need to be addressed in the development of a coordinated and integrated community hospice care system. The findings speak to an overarching need on Gabriola for a Hospice Care Community HUB that consists of a network of care for Gabriola residents, with a paid coordinator and administrative support. This includes, development of a network that harnesses the resources of many existing organizations that can support palliative care patients and their families.

## Table of Contents

Background	.....4
Public Forum: <i>Understanding How Compassionate Communities Can Support Those Needing Hospice Palliate Care</i>	.....5
Key Themes on Hospice Community Care Supports – A Summary of Working Group Reports	.....7
Evaluation of the Forum	.....11
Next Steps	.....11
Appendices	.....11

## Background

### a. Problem Identification

Two driving forces emerged concurrently. Participants at the 2018 Fall Forum of the Gabriola Health and Wellness Collaborative (GHWC) identified the need for support of the dying and their families as one of two community priorities. At the same time, Doctors at the Gabriola Medical Clinic identified that many of their patients were being transferred to Nanaimo Hospital prior to death while the patient's preference would have been to die at home if there had been adequate access to professional services and home supports for them and their families.

### b. Initiative Leadership and Funding

As a member of the GHWC the Rural and Remote Division of Family Practice (RRDOFP), Nancy Rowan agreed to take the lead in addressing the needs of palliative patients and their families on behalf of the Collaborative. Dr. Tracey Thorne, physician lead and Nancy Rowan, Coordinator with the RRDOFP applied for and were awarded funds to establish a process to enable the development of a coordinated and integrated system of palliative care on Gabriola Island. (The funding for this initiative ends March 31, 2019). A working group of 15 people was convened with representation from family medicine, Island Health specialized services team (nurses, social workers, palliative care specialists), Gabriola Healing Arts community, trained hospice volunteers, interested community members, BC emergency services and a patient representative.

### c. Data Collection and Needs Assessment

The working group agreed upon the following definition of palliative care to guide their work. "Palliative care is a philosophy of care addressed to a whole person, their families, friends and care givers, it is not a disease and it aims are to relieve suffering, to improve quality of life and to promote dignity and meaning when a cure is not possible".

Hospice palliative care is aimed at relief of suffering and improving the quality of life for persons who are living with or dying from advanced illness or are bereaved. Canadian Association of Hospice Palliative Care

It is generally recognized that hospice societies/programs are community-based organizations that facilitate trained volunteers in providing psycho-social care and bereavement support. This may take the form of one-to-one companionship, support groups, self and wellness care, equipment loan, information and resources and community education. On the other hand, palliative care generally refers to the professional team of support that may include the family physicians, palliative physicians, nursing, social work and home support. These

two systems interfaces in the development of a care plan to support the unique needs of each patient/family.

In order to educate themselves on hospice organizations, the working group undertook a review of the goals and services offered by other hospice organizations within the Vancouver Island Region. A working relationship was initiated with the Vancouver Island Federation of Hospices, the BC Center for Palliative Care and several local hospice organizations. One committee member led a group of volunteers on a field visit to the Port Alberni's TY Watson House.

The working group deliberated to identify gaps in services and assets/strengths that could be built upon. In addition, a focus group with family members of people who passed within the past year was conducted. The findings of both groups were similar. There were deficits in access to after hours care by trained professional staff, it was difficult to access needed information and resources and a system of community supports to help families with the practical and psychosocial aspects of care was missing.

d. Working Group Priorities and Actions

In keeping with its goals of developing a coordinated and integrated system of hospice palliative care two parallel initiatives were initiated. One initiative included enhancing patient/family access to a coordinated system of professional services including advanced training for physicians and professional staff in palliative care. The second included initiating a process leading to the development of a Gabriola community-based hospice care program to meet practical, psychosocial and spiritual needs patients and their families. Ultimately, the goal is to have these two initiatives unite into a seamless system of care and support.

Steps taken towards meeting these developmental goals include:

1. Partnering with Island Health (IH) regional palliative care services to identify and address gaps in services, and
2. Collaborating with community members and Gabriola organizations in developing a hospice care volunteer program to support terminally ill patients and their families.

It was this second goal that led to the public forum.

## **Public Forum: *Understanding How Compassionate Communities Can Support Those Needing Hospice Palliative Care***

This forum was held on October 10<sup>th</sup>, 2018 at the Gabriola Fire Hall meeting room. The event was sponsored by the Gabriola Health Care Foundation (GHCF) and organized by the members of the GHCF Health Services Committee (HSC) (Lynne Young, Dave Innell and Vicky Scott). The event was facilitated by Ms. Nancy Rowan from the Rural and Remote Division of Family Practice and Dr. Vicky Scott, as a member of the GHCF and Health Services Committee.

### a. Purpose

The goals of the forum were two-fold.

1. To contribute to the understanding of the need for personal and community development to support terminally ill patients and their families.
2. To garner public input into the design and implementation of Gabriola based hospice care program.

### b. Agenda

The format for the public forum included a welcome by Dr. Vicky Scott on behalf of the GHCF and opening remarks by Ms. Nancy Rowan on the background and purpose of the event. This was followed by a presentation on “Establishing a Compassionate Community Network” by Dr. Eman Hassan from the BC Centre for Palliative Care. Dr. Hassan’s talk was followed by a group breakout session.

#### Guest Speaker

Dr. Hassan is the BC Centres for Palliative Care Director of Public Health Initiatives and is leading the Compassionate Communities and Advance Care planning initiatives. Her presentation highlighted the need to empower individuals and families to have conversations about end of life needs and wishes; and, the need for the development of community-based supports to help make the end of life experience a positive one. See appendix A for a copy of her presentation and appendix B for description and link the video on “*Compassionate Neighbours*”.



Photo: <https://www.bc-cpc.ca/cpc/eman-hassan/>

### c. Workshop Format

A number of table topics has been identified ahead of time during the problem identification phase, and participants self-selected the tables they wished to participate in. Each table identified a facilitator from within their group who made notes on flip chart paper and reported the small group finding to the larger group. Each group responded to questions and the reporting was followed by an open discussion.



Table topics were:

1. Administration and Coordination
2. Companionship Palliative Patients/Families and Practical Supports
3. Complementary Therapies and Healing Arts
4. Bereavement Support
5. Wild Card (any topic of the groups choice)

Tables were requested to address the following questions:

1. Where are we now?
2. What do we have?
3. What can we do?
4. Who should be involved?

## Key Themes on Hospice Community Care Supports – A Summary of Working Group Reports

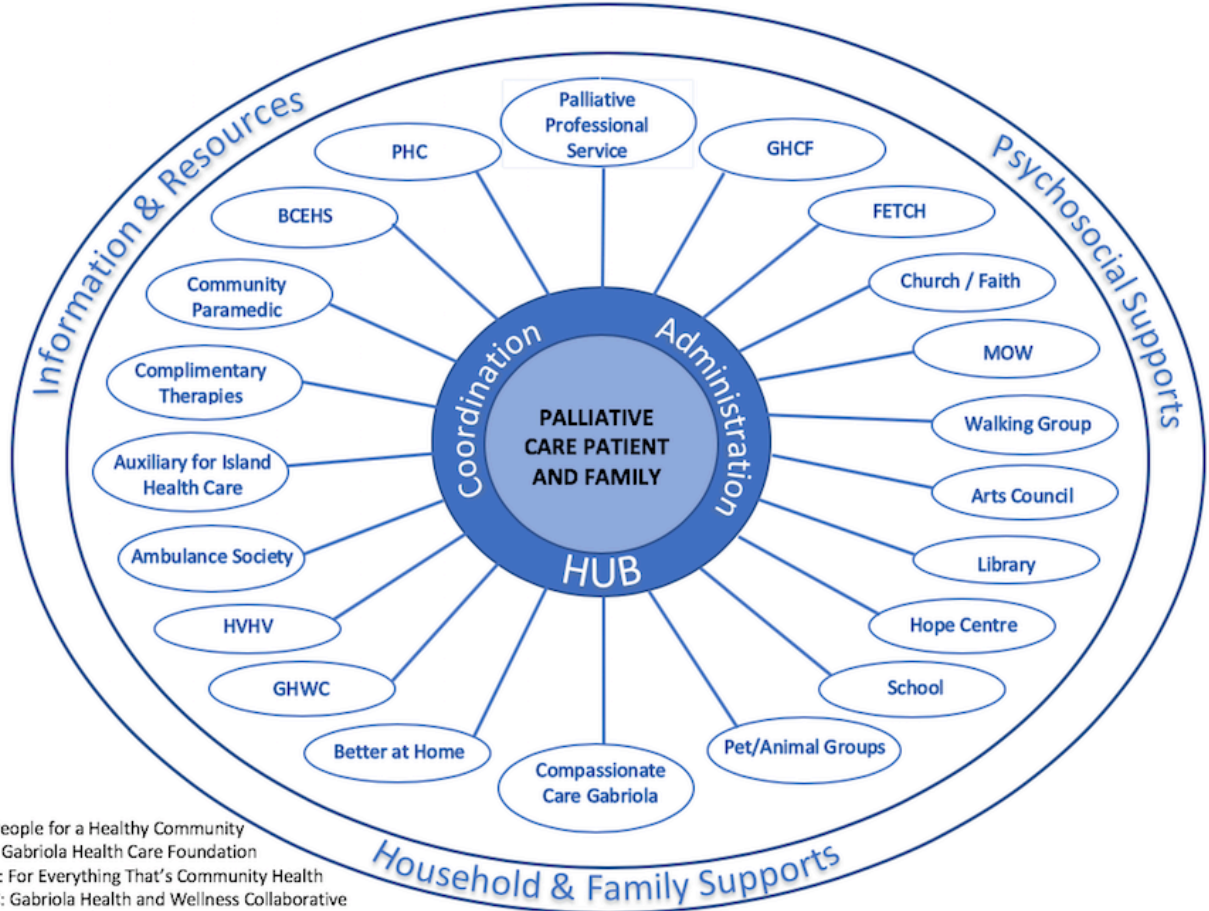
The original content of the work group findings can be viewed in Appendix C. The data was analyzed for key themes and priority actions. The analysis of the findings from the workshop participants falls under four themes 1. Administration and Coordination; 2. Information and Resources; 3. Psychosocial Supports; and 4. Household and Family Supports. Each speaks to a wealth of existing resources and identified gaps that need to be addressed in the development of a coordinated and integrated community hospice and palliative care system. The findings



speak to an overarching need on Gabriola for a Hospice Care Community HUB that consists of a network of care for Gabriola residents, with a paid coordinator and administrative support. This includes, development of a network that harnesses the resources of many existing organizations that can support palliative care patients and their families. Potential network members are depicted in Figure 1.

Figure 1

Proposed<sup>1</sup> Gabriola Community Hospice Palliative Care Model



KEY:

- PHC: People for a Healthy Community
- GHCF: Gabriola Health Care Foundation
- FETCH: For Everything That's Community Health
- GHWC: Gabriola Health and Wellness Collaborative
- HVHV: Hospice Volunteer Home Visitors
- MOW: Meals on Wheels
- BCEHS: BC Emergency Health Services (Fire, RCMP, Paramedics)

<sup>1</sup> Model requires validation and role definitions.



## Key Themes

### 1. Administration and Coordination

- a. HUB to coordinate Community Hospice Palliative Network (e.g., PHC) – needed
- b. Paid coordinator and admin support (coordination of volunteers, training, one-call access to resources, data base, professional standards, navigator/connector, etc.)
- c. Palliative Care Working group (to develop an integrated system of palliative care, establishing a process for the development of a community hospice palliative care program) - existing until March 2019
- d. Financial resource acquisition and fund raising (funds can only go to a registered non-profit society) - needed



N.B. Hospice societies and/or programs are guided by provincial standards as outlined on the following web site:

[http://www.virtualhospice.ca/Assets/bchpcastandardscompleted\\_20081127165936.pdf](http://www.virtualhospice.ca/Assets/bchpcastandardscompleted_20081127165936.pdf)

### 2. Information and Resources

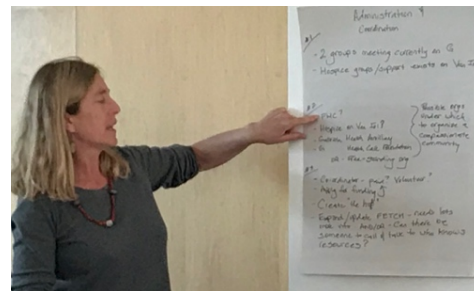
- a. For Everything That's Community Health (FETCH) – existing but needs to be enhanced
- b. Palliative services booklet (Nanaimo) - existing
- c. Palliative services booklet (Gabriola) – needed
- d. Library – existing but needs a focused section (videos, TED talks, e.g., “My Stroke of Insight”)
- e. Death Café - existing
- f. Church / Faith – bereavement resources?
- g. Physician offices – brochures?
- h. Off-island hospice – Nanaimo Hospice Association



- i. Doctors on island
- j. Complimentary therapies - existing
- k. Gabriola Ambulance Society – existing (equipment)
- l. Palliative government benefits - existing
- m. “Hello” game from BC Centre for Palliative Care – bring to Gabriola
- n. Annual advanced care workshops – needed
- o. Morgue (care of the body overnight) – needed [Note: later found that a system does exist to deal this situation]
- p. Death doula (create ceremony etc.) – exists?
- q. Power outage support (generators for medical equipment, etc.) - needed

### 3. Psychosocial Supports

- a. Trained hospice home visitors – some with training but not part of an integrated Gabriola system
- b. Support and continuing education of volunteers – need regular meetings
- c. Support at night by a volunteer for the dying person (by trained volunteer) - needed
- d. Death, dying and Bereavement – needs re-development (group sessions, phone follow-up, walking group, support for men, communication skills)
- e. Communication training, i.e., “Serious Conversations” (being a good listener)
- f. Caregivers’ Support Group – needs to be brought back and reinvented
- g. Special programs, e.g., Legacy Art program, arts, music and theatre programs etc.
- h. Complimentary therapies – exists (Gabriola Healing Arts, practitioners and programs)
- i. Support for supporters - needed
- j. Mindfulness (family mediation, disputes resolution, social attitudes to death process, approaches to alleviating stress, young children participation, education of parents, kids’ respite)- needed



### 4. Household and Family Supports

- a. Meals on Wheels - existing
- b. Better at Home - existing
- c. Church / Faith – existing
- d. Facilitated circle of family, friends, neighbours – needs development
- e. Trained hospice home visitors – some existing but need local training programs that is adheres to provincial standards
- f. Financial counseling – needed
- g. Acts of kindness – needs coordination (chopping wood, reading, soup, muffins, music, etc.)

## **Evaluation of the Forum**

An evaluation was conducted at the end of the forum and 37% of the participants completed the evaluation form (18 out of 49). Half of the 18 participants who completed the evaluation form stated that they heard about the talk through the Sounder newspaper and half through friends, with another five sources mentioned (data not mutually exclusive). Eighty-eight percent reported that “Most” or “Some” of the content was new to them. While 72% said that they could hear “All” that the presenter said, 22% said they only heard “Some” and five people provided suggestions such as using a microphone or making sure those who are hearing impaired have the opportunity to sit at the front. Most (89%) said the Fire Hall meeting room was a good location but others reported poor acoustics, making it difficult to hear each other during the working group session. Most (83%) said that they found the workshop exercise useful, but a few commented on the poor acoustics and the difficulty in hearing others during the workshop exercise. Sixty-seven percent of participants said that they would make changes based on what they learned, and another 28% said “Maybe” to making changes. Comments about the nature of such changes included being involved in the development of a Hospice Palliative Care Program on Gabriola or taking training related to palliative care issues on Gabriola. Eighty-three percent of participants said that they would be interested in other public talks on health issues and suggestions included topics such as hospice care, advanced care plans, aging in place and palliative issues, including using the “Hello” game from the BC Centre for Palliative care. Seventeen percent reported that they had questions that were not answered, and these included: the need to focus on how to develop the non-governmental system, more information about websites for groups and more about volunteer training.

## **Next Steps**

The role of the working group will continue to develop processes that support an integrated and coordinated system of professional and community-based services for palliative patients and their families. This report addresses the development of the community portion the proposed hospice program.

The Palliative Care Working Group met in October 19<sup>th</sup> and agreed on the following next steps.

1. Facilitate the creation of an administrative hospice HUB for a Gabriola Island
2. Facilitate training of volunteers
3. Facilitate the creation of a local data base of resources

## Appendices

- A. *“Establishing a Compassionate Community Network”* by Dr. Eman Hassan
- B. Compassionate Neighbourhood Video Link
- C. Workshop Group Facilitator Reports
- D. Evaluation of the Forum

### Appendix A

*“Establishing a Compassionate Community Network”* by Dr. Eman Hassan



Gabriola Public  
Forum 2018-Eman H

### Appendix B

Compassionate Neighbours Video Link

Compassionate Neighbours is a social movement of trained local people who are empowered to be more compassionate in their local communities. They provide emotional and social support for community members who are isolated and elderly or experiencing chronic or terminal illness.

Link to award winning compassionate neighbours program by St Joseph’s Hospice, London, England: Choose “Stories” in menu bar at the top, then “Videos”, at:

<http://compassionateneighbours.org/>

## **Appendix C**

### Workshop Group Facilitator Reports

#### **1. Bereavement:**

Where are we now?

- Alzheimer's support group and Walking Group in Nanaimo

What do we have?

- Nothing

What can we do?

- Initiate a Talk and Walk Group
- Develop communication skills
- Bereavement follow-up by phone
- Support for men

Who should be involved?

- Trained volunteers

#### **2. Companioning Palliative Care Patients/Families and Practical Support**

Where are we now?

- Several ad hoc support groups and N/W's
  - FETCH (For Everything That's Community Health) website
  - Off Island Hospice
  - Palliative Working Group
  - Doctors at clinic
  - Caregivers support group (needs to be brought back and reinvented)

What can we do?

- Hospice training on island
- Host game mentioned by speaker from BC Palliative Care
- Healing Arts Group
- Annual advanced care workshop
- Organize a structure to coordinate and foster with other organizations
- Support at night – fear
- First night alone – someone to be with
- Regular companion – comfort
- Acts of kindness – reading, soup, muffins, guitar, wood
- Involve churches
- Training to cover not to talk over or getting involved with family drama
- Our library resources for support
- Bereavement sessions on island
- Recognizing potential needs in neighbourhood

- A list of resources pods
- Support for supporters
- Music – play guitar

### 3. Wild Card

Where are we now?

- Isolation (support not offered by social network of the individual)
- Home care not adequate (scheduling issues)

What can we do?

- Neighbourhood circles of care
- Morgue (for families not comfortable with keeping body overnight) [Note: later determined that a system does exist to deal with this situation]
- Educational opportunities for choices
- Death doula (help create ceremony; changing the attitude of the approach to death; facilitating as a parallel to birth)
- Mindfulness (facilitator for family disputes; educating social attitudes to include death process; adapting approaches to alleviating stress; children participation; education of parents; kids' respite)
- How to stay at home during power outages (mobilizing generators for feeding pumps, oxygen etc.)
- Reading list of resources (also videos, TED talks [My Stroke of Insight])
- Death café interest
- Regular meeting to share education among ourselves and spreading the participation

### 4. Administration and Coordination

Where are we now?

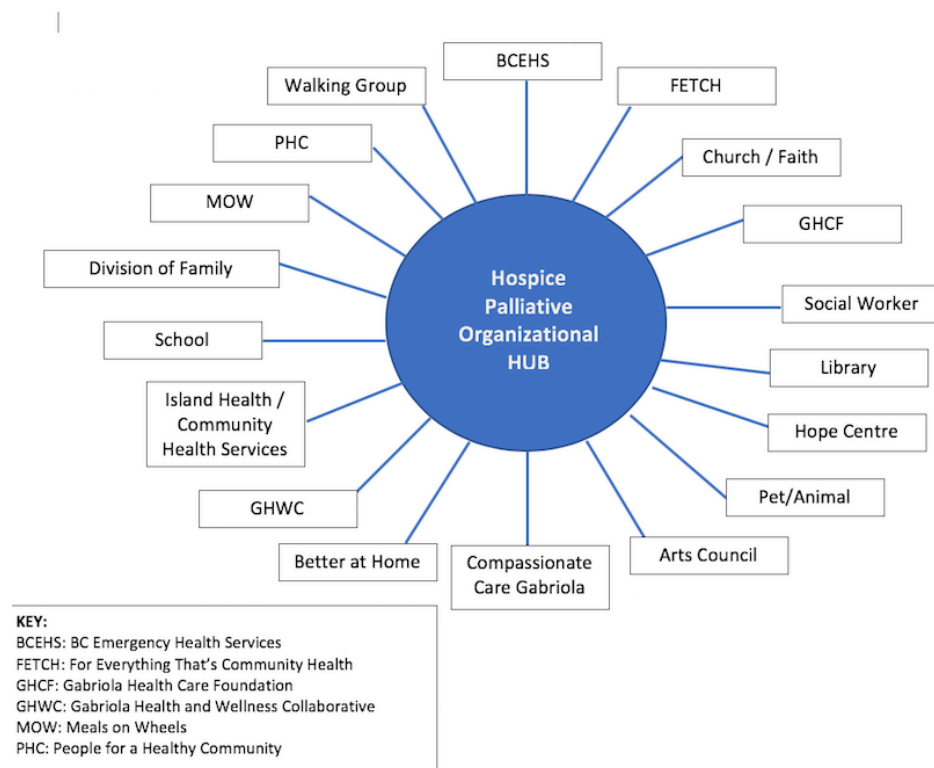
- Two group meeting concurrently on Gabriola
- Hospice groups / support on VI

What can we do?

- Possible organizations under which to organize a compassionate community:
  - PHC?
  - Hospice on VI?
  - Gabriola Health Care Auxiliary
  - Gabriola Health Care Foundation
  - Or Free-standing Organization
- Coordinator (paid/volunteer?)
- Apply for funding
- Create the HUB
- Expand/update FETCH (needs lots more information)
- Someone to call to talk with who knows the resources
- Post-death support needs (local walking group)

- Library (very few helpful books in local library)
- Find a way to provide better resources
- Identify core elements of a palliative care HUB:
  - Single point of contact
  - Navigator/connector
  - Palliative care working group
  - Admin coordinator/director – non-volunteer
  - Funding sources
  - Data base
  - Paid admin/secretary
  - Referral center
  - Ensure professional standards (Education; Qualifications)
  - Volunteer training
  - Debrief team members
  - Website

**Figure 2: Original Working Group Model of Potential Organizations For a Hospice Palliative Care HUB**



## 5. Complimentary Therapy / Healing Arts

What do we have now?

- Gabriola Arts Council (has a Healing Arts program; Arts Music and Theatre program)
- Practitioners of various healing arts modalities (Healing Touch; Reiki; singing therapy groups; Death Café)
- Volunteers interested but no coordination
- Alzheimer's support group

What can we do?

- Add legacy arts program and other programs mentioned by today's speaker
- Funding for complimentary care
- Link complimentary therapies with medical professionals on Gabriola (workshop for MDs and Nurses)
- Increase awareness of what is available
- Support for patients and caregivers
- Volunteers training plus coordinator
- Complimentary practitioners could donate workshops or sessions to increase awareness
- Complimentary practitioners should be funded and part of the holistic care/support plan



## Appendix D Evaluation Results

### ***Palliative Care Presentation and Workshop***

By Dr. Eman Hassan, Gabriola Fire Hall Meeting Room, October 10, 2018

Question	Options	Results (n=18) <sup>1</sup>	Other/Comments
How did you hear about this talk ( <i>check all that apply</i> )? ( <i>Note: results not mutually exclusive</i> )	Sounder Friend	9 (50%) 9 (50%)	Other: <ul style="list-style-type: none"> <li>○ Palliative Care Committee</li> <li>○ At another session with those who had recently had a loss.</li> <li>○ Through the compassionate Gabriola group</li> <li>○ On committee</li> <li>○ Volunteer palliative group.</li> </ul>
Was there content that was new to you ( <i>check one</i> )?	Most Some None	3 (16%) 13 (72%) 2 (11%)	<ul style="list-style-type: none"> <li>○ Definition of palliative and BC programs.</li> </ul>
Could you hear the presenter? ( <i>check one</i> )	All Some None 'Missing'	13 (72%) 4 (22%) 0 (0%) 1 (5%)	<ul style="list-style-type: none"> <li>○ Needed a bit more room as great turnout!</li> <li>○ However, would have been better with a microphone.</li> <li>○ Very difficult for those who are hearing impaired.</li> <li>○ I'm hearing impaired, so I sat at the front of the room.</li> <li>○ Perhaps a mic.</li> </ul>
Was this a good location for the talk ( <i>check one</i> )? ( <i>Note: results not mutually exclusive</i> )	Yes No 'Missing'	16 (89%) 2 (11%) 1 (5%)	If no, why: <ul style="list-style-type: none"> <li>○ Acoustics were poor – too noisy.</li> <li>○ Large groups need to break into another area. The noise level was too great in discussion time. There needs to be a microphone used when there is a large group.</li> <li>○ Need speakers' technology for audio-visual presentations.</li> </ul>
Did you find the workshop exercise helpful? ( <i>check one</i> )	Yes No Some 'Missing'	15 (83%) 0 (0%) 2 (11%) 1 (5%)	If no, why: <ul style="list-style-type: none"> <li>○ Wanted to table hop and couldn't.</li> <li>○ Hard to hear one another at times.</li> <li>○ Acoustics.</li> <li>○ An excellent design but not for a hearing-impaired person.</li> </ul>
Do you plan on making any changes based on what you learned from this talk and workshop?	Yes Maybe No 'Missing'	12 (67%) 5 (28%) 1 (5%) 1 (5%)	<ul style="list-style-type: none"> <li>○ Would like to be involved in developing.</li> <li>○ Continue creating community participation. I would like to get training on Gabriola palliative care issues.</li> </ul>
Would you be interested in other public talks on health issues?	Yes Maybe No	15 (83%) 3 (17%) 0(0%)	Topics of interest: <ul style="list-style-type: none"> <li>○ Hospice care</li> <li>○ Advanced care plans BC Centre for Palliative Care questions.</li> </ul>

<sup>1</sup> Total attendance = 42 (Plus 1 speaker and 2 facilitators)

			<ul style="list-style-type: none"> <li>○ On aging in place as I move on in my life.</li> <li>○ Hello game.</li> <li>○ On palliative issues.</li> </ul>
Do you have any questions about palliative care that were not answered? If so, please write you questions under “Comments” or on the back page.	Yes No 'Missing' ,	3 (17%) 5 (28%) 10 (56%)	<ul style="list-style-type: none"> <li>○ Would like to focus discussion on practical issues in setting up a hospice.</li> <li>○ “Compassionate Community” is a fairly vague concept – already present to some degree on Gabriola.</li> <li>○ My concern is a protective one. The system is so great an idea. How to develop the non-governmental system? It needs to be nurtured while it grows and develop.</li> <li>○ Websites for groups and questions.</li> <li>○ We need more volunteer training. The Hello game is a great idea.</li> </ul>

## Evaluation Summary

Thirty-seven percent of the participants completed the evaluation form (18 out of 49). Half of the 18 participants who completed the evaluation form stated that they heard about the talk through the Sounder newspaper and half through friends, with another five sources mentioned (data not mutually exclusive). Eighty-eight percent reported that “Most” or “Some” of the content was new to them. While 72% said that they could hear “All” that the presenter said, 22% said they only heard “Some” and five people provided suggestions such as using a microphone or making sure those who are hearing impaired have the opportunity to sit at the front. Most (89%) said the Fire Hall meeting room was a good location but others reported poor acoustics, making it difficult to hear each other during the working group session. Most (83%) said that they found the workshop exercise useful, but a few commented on the poor acoustics and the difficulty in hearing others during the workshop exercise. Sixty-seven percent of participants said that they would make changes based on what they learned, and another 28% said “Maybe” to making changes. Comments about the nature of such changes included being involved in the development of a Hospice Palliative Care Program on Gabriola or taking training related to palliative care issues on Gabriola. Eighty-three percent of participants said that they would be interested in other public talks on health issues and suggestions included topics such as hospice care, advanced care plans, aging in place and palliative issues, including using the “Hello” game from the BC Centre for Palliative care. Seventeen percent reported that they had questions that were not answered, and these included: the need to focus on how to develop the non-governmental system, more information about websites for groups and more about volunteer training.