Patient Advisors and Interior Health: Partnerships that work!

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Every person matters

Identifying the need to engage

* Building a strategy and vision for palliative care in IH
* Integrated vs End Knowledge Translation: Need for patient voice in the planning right from the start and throughout the development and evaluation process
* Seeking more than tokenism… consultation with the engagement leader… so we identified need for a group!

Identifying the fit: Mutual Interviews

* Articulate specific needs for patient voices (W5)
  * *pre-consultation with Engagement Leader is very helpful*
* Submit detailed written engagement request to BCPSQC (Carol)
* Carol put out the invitation to volunteers
* Mutual call: Joint exploration of needs and interests
* Final decisions: start the work with interested group.

Identifying the 3 projects

* 3 important pieces of work identified in the IH Palliative Care Strategy:
  * Standardize the PC program information to initially hand out to new individuals/families on the program.
  * How to create a library of resources for all the other information that will be needed in the palliative journey?
  * Redesign the IH external website to be more user friendly for the public

* Timelines: Start in May 2015 and finish by December 2015.

How we worked together

<u>Discuss how we want to be together</u>:

* Create a safe place for people to speak, ask questions
* Encourage all comments and feedback
* Respectful conversation – one at a time, all encouraged but not forced to contribute.
* Check-ins re personal journeys and reactions.

How we worked together

Organizational details:

* Worked by teleconference and Webex – we never met!
* Purpose – defined, specific, context driven and explained, revisited, reframed
* Commitment – originally 8 PVN volunteers, restructuring, final stages =5
* Be organized, but informal – recapture last meeting, follow-through on edited changes between meetings.
* Do the heavy lifting for developing publications – bring drafts and mockups
* Timelines – tried to honour as much as possible, seek permission for more.
* Opportunity for synergy! Judy Nicol "borrowed" the group to review MOST public education materials with their permission.

Regional Palliative Program Brochure

Hospice Palliative Care services are provided by a team of caregivers that can include health care professionals, volunteers and spiritual advisors.

Services can include:

- Medical care with a focus on pain and symptom control
- Access to health care professional support 24 hours/day x 7
- Medical supplies and equipment as needed
- Counselling and social support available for the individual and family
- Guidance and support with issues about end of life
- A break (respite care) for caregivers who regularly care for the individual

Your personal Hospice Palliative Care team may include:

Home Health RN/Nurse Practitioner
contact information:

After Hours Palliative Nursing Service 1-877-800-8882 only available 9pm-8am Pacific Time

Physician/Specialist
contact information:

Other:

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Hospice Palliative Care Program

Your doctor has referred you to a special program that will support you and your family as your health condition and needs change.

Hospice Palliative Care is a compassionate approach that provides medical services, emotional support and spiritual resources for individuals during the last stage of life when cure is no longer possible. Some examples of these illnesses may be cancer, end stage heart or lung disease or dementia.

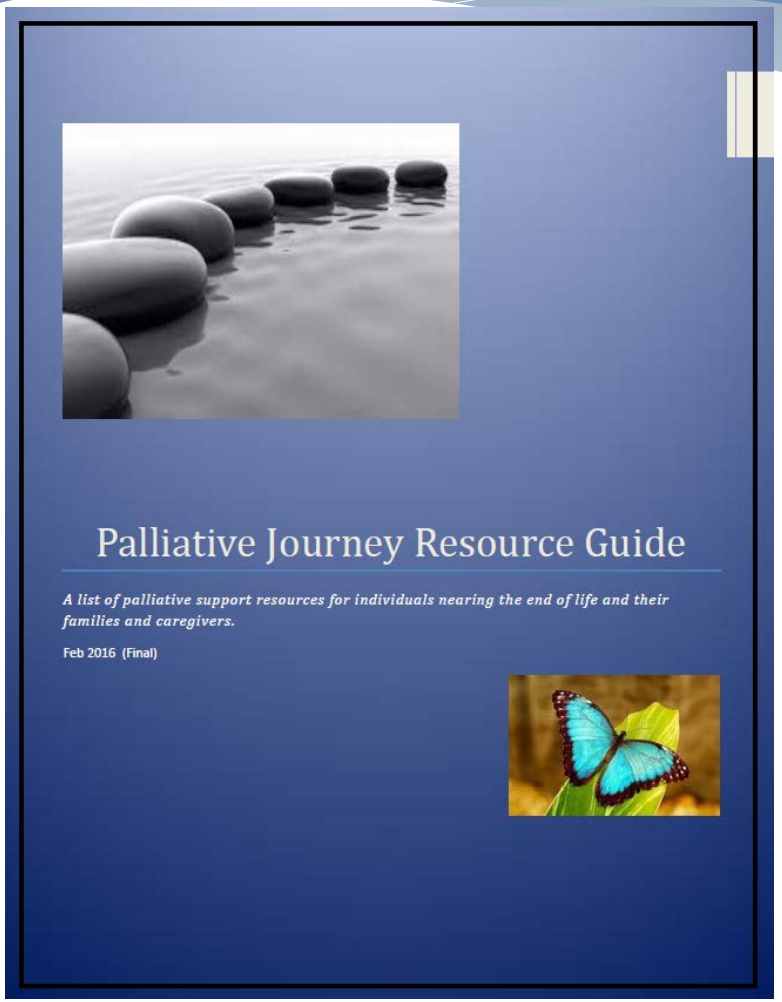
The goal of this program is to improve quality of life, not just the body but also mind and spirit. Hospice Palliative Care can also help individuals cope with their feelings about end of life.

Hospice Palliative Care can support family members who manage the practical details and emotional challenges of caring for a dying loved one.

This program can provide support through all stages of advancing, life-limiting illness. We can help with management of symptoms, pain or side effects from treatments.

- Language
- Graphics
- Lay out
- Tone

Palliative Journey Resource Guide

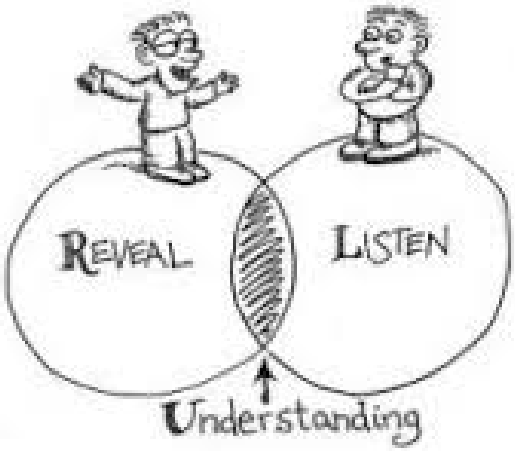


* Timing
* Sign posting
* Flexibility of needs
* Intimacy
* Usefulness

Revising IH Public Website

- Public information
- Presentation and Impact
- Language
- Graphics
- Tone and Intimacy
- Coherency and Support

Mutuality



- Public-friendly, targeted and comprehensive resources
- Shared understanding
- Partnership
- Success

- Valued contributions
- Shared experiences and insights
- Shared understanding
- Partnership
- Success

Questions? Discussion?

Common Questions Raised

* *How are patients used in development work?*
* *How do patient advisors help?*
* *Does it take longer to get the work done?*
* *What does it cost?*
* *How does the patient family advisor impact the team?*
* *What are the challenges/successes?*
* *How have they been used in the past on projects?*
* *How receptive is IH in partnering with patient voices networks?*
* *What does patient and family engagement mean to IH?*