

2011

Grande Prairie Hospice Palliative Care Society



The survey and report was
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Background

In January 2011, The Grande Prairie Hospice Palliative Care Society decided to conduct a survey to determine the quality of Hospice Palliative Care service and supports that people have received and to collect people’s recommendations and suggestions for future services and supports. It is the society’s intent to use community input to drive decisions on how best to meet our mission:

“To establish and maintain expert end-of-life care for community members with a terminal illness & to provide support for their families

- We are a voice for the community
- We are an ear to public need
- We are a hand in action”

The society launched the survey May 1, 2011 and this report is from data collected to June 8, 2011. It was agreed that the collection of community input through an open ended survey was the best route to ensure constant feedback from our community. Annual reporting on the anniversary of the launch will roll up new data.

Survey, community consultations, focus groups

In an effort to address the customary low response rate of surveys, the Society agreed to try a combination of written and online surveys.

Written surveys were distributed at request and the online survey was organized through Survey Monkey and advertised on radio and newspaper as well as extensive email lists.

We used a person centered process entitled “Working Together for Change”. In order to capture what was truly on people’s minds and not limit them to specific questions that are typical of traditional surveys, we based the survey on four broad questions:

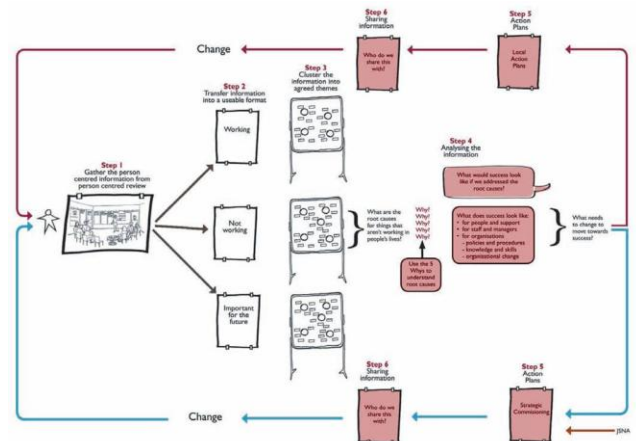
If you have had experience with palliative hospice care list 3 things that worked well

If you have had experience with palliative hospice care list 3 things that did not work well

If you have had experience list 3 suggestions for the future

If you have had no experience list 3 suggestions for the future

Respondents were asked to share their top three priorities for each question. The information was then clustered into themes and analysed to capture best practice, areas requiring change and suggestions for strategic planning. **Note: this survey is not Grande Prairie specific. Participants were asked of their experiences in general so this reflects hospice palliative care experiences across our country.**



Response rate

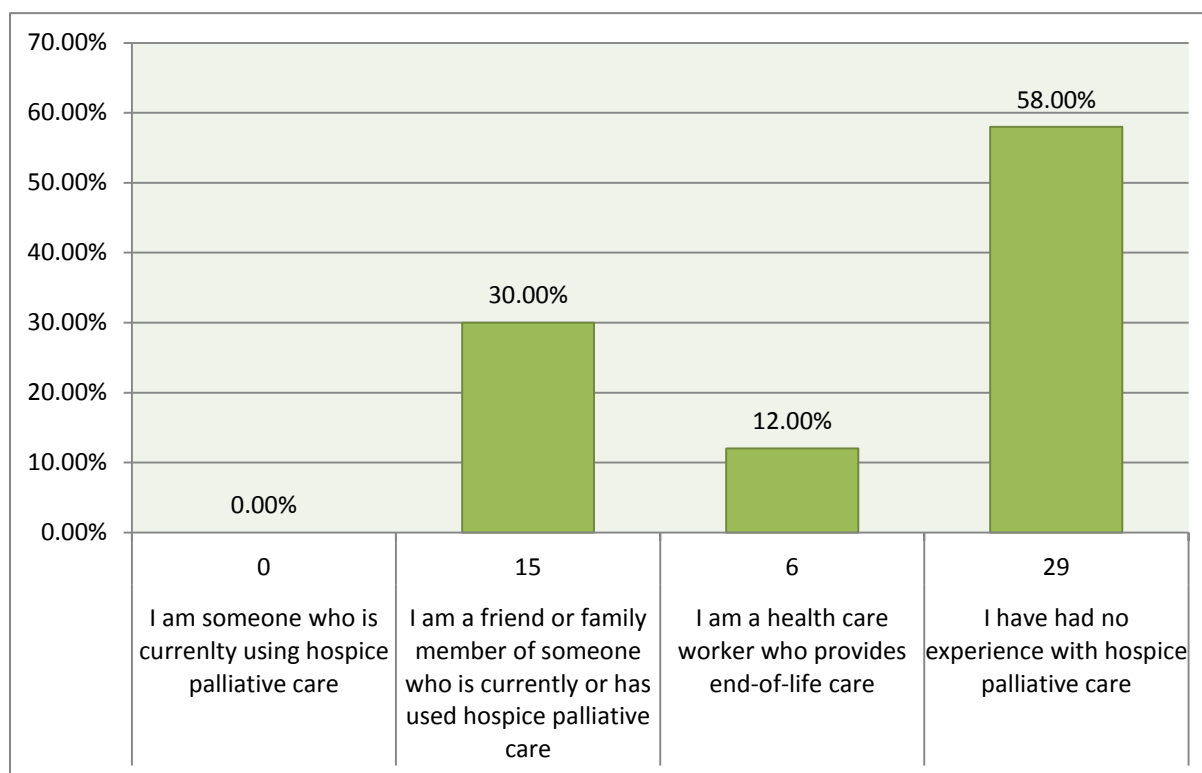
50 persons responded

1 person did not respond

I am someone who is currently using hospice palliative care	0	0.00%
I am a friend or family member of someone who is currently or has used hospice palliative care	15	30.00%
I am a health care worker who provides end-of-life care	6	12.00%
I have had no experience with hospice palliative care	29	58.00%
	50	100.00%

Total number of respondents

The total number of survey participants is distributed in the following manner:



Survey Results

What is working?

Top three areas of interest were:

1. Well trained compassionate medical professionals
2. Compassionate care for families
3. Personal comfortable environment

Survey participants provided the following examples of what is working:

<p>Well trained, compassionate medical professionals</p> <ul style="list-style-type: none"> • Well trained staff that understand end of life issues and provide appropriate care • Experienced nurses comfortable with the dying process • Getting appropriate information from resources that are available to us as professionals in the field. • Nurses, Physicians, Homecare nursing and social workers trained in palliative care plus a chaplain that can support person from all religions • Good training through workshops • Pain and other symptoms were controlled • Staffing--starting to place staff there who were interested in the field. They were wonderful • Nurses were exceptional in caring for patient • The staff were very caring <ul style="list-style-type: none"> • Home Care nurses were compassionate • The Nurses • Took very well care of my sister • 24 hour on call service • Always someone there when we couldn't be • Dedicated health professionals • Client Centered Care • Home Care assisted with equipment necessary to keep our family member at home • Quality medical resources (especially pain mitigation) • Access to medication <p>Family - Inclusion</p> <ul style="list-style-type: none"> • Ability to spend as much time there as possible. Never felt like I had to leave at a certain time. • Being able to stay with my family member as much as I liked 	<p>Palliative care physician on staff</p> <ul style="list-style-type: none"> • Homecare/Dr. Barreth • Palliative Care physician to order medications and work with patient and family to provide comfort • Having a physician available who specializes in palliative care • Having a specialized Doctor work in the area • The doctor <p>Effective Communication</p> <ul style="list-style-type: none"> • Communication between staff & family • One on one connection with staff • Doctors always kept us updated on happenings <p>Compassionate care for family</p> <ul style="list-style-type: none"> • Health professionals that include family and loved ones in the care and decisions • Willingness of nurses to talk to me, explain things, encourage the asking of questions. • Health care providers trained specifically for this emotionally heavy job • Experienced Palliative Care nurses providing regular comfort care • Communication with family and healthcare providers • Nurses always were concerned of family and offered hugs when we seemed to need them • The willingness of some of the nursing staff to sit and talk to family members • Complete access to patient (family member) • atmosphere of encouraging family and friends to be around • The thoughtfulness • My sister was a nurse and I know she would like to have the help to the end
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<p>The hospital setting allowed 24 hour access to loved ones and provided sleeping arrangements for family member</p> <ul style="list-style-type: none"> • Family being able to be there day or night 	
<p>Personal, comfortable environment</p> <ul style="list-style-type: none"> • Ability to make the room as personal as possible. • Palliative room very comfortable even though a little small, anything we needed was available • The ability to make the room personal for my family member, including the coffee pot • Guest accommodation in unit for our family • Appropriate facilities • A non-hospital/institutional environment • Ease of moving clients from home to hospital for final days, weeks before death 	<p>Person centered care/Team approach</p> <ul style="list-style-type: none"> • Care very patient centered--patients able to be believed about their level of pain, and treated accordingly • Outstanding care provided • Advocacy for the value of hospice palliative care • Team approach and outside resources such as GPHPCS
<ul style="list-style-type: none"> • Desire and good intention of community members to help in any way they can for palliative clients 	<p>Care about spirituality</p>

What is not working?

Top three areas of interest were:

1. Palliative care is not a main focus
2. Physical setting
3. Lack of family support

Survey participants provided the following examples of what is not working:

<p>Palliative care is not a main focus</p> <ul style="list-style-type: none"> • Lack of staff assigned to specifically and trained in palliative • Inconsistency in care and knowledge deficits • The nurses did not seem to know what to do • Having family Doctor only provide treatment • Limited nursing staff • Not enough staff on duty • Lack of trust for competency • Hospital hospice care for my mother was extremely interventionist • Lack of recognition from AHS regarding hospice palliative care in northern Alberta • Communication breakdowns between all involved in actual care of client • Hard to get referred by medical professionals • I think when someone so ill is sent home to try, but the pain becomes so bad they must return to the hospital I don't believe sitting in 	<p>Physical setting</p> <ul style="list-style-type: none"> • Although all the staff did everything they could to make family members comfortable, the rooms need to be set up differently, i.e. comfortable chairs, microwave in room, and double hospital beds, if there are such things! This would provide much needed comfort for patient and spouse. • The furniture was very uncomfortable and sterile • The setting was very "clinical" • Room • The furniture was very uncomfortable and still very sterile - like a hospital room. A rocking chair or recliner would be more comfortable. • Set up differently, e.g. actual bed (not cot) for family members, and possibly double hospital beds, if they exist. Microwaves and comfortable chairs, and the ability • I believe more home like settings for patients and family would be beneficial. Many hours spent at
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<p>emergency waiting to see a doctor who has no relationship is right. The patient should be able to be admitted, if room, directly to someone who can help them immediately.</p> <ul style="list-style-type: none"> • Perhaps not able to administer meds in a timely fashion • Going into the hospital early in prognosis • Need 24 hour consistent help which isn't available. Yes, Homecare is on call but cannot handle everyone and they can only do what they have orders for. If there is a need for any change of orders you must wait for a Dr. to give these orders. • When medication was requested the Doctor did not come to do an assessment • Funding limitation • Not enough support for professional staff and caregivers following care of client after their deaths 	<p>the hospital and rooms that were more comfortable not only for patient but family members as well</p> <ul style="list-style-type: none"> • Limited space in a small room • Old, decrepit unpleasant looking facility • There wasn't much room for family • Equipment • Rundown, and sort of dangerous
<p>Lack of family/person support/inclusion</p> <ul style="list-style-type: none"> • Isolation of the patient. Not sure how often human contact would have occurred if the family wasn't available. Room was very far from nursing station. • No support for the family in any way- education, psychological, etc • The hospital nurses, at the time, did not provide information or guidance to my sibling or the family • The lack of welcoming when first entering the ward. The elevator doors open right at the nurse's station, but the staff do not acknowledge visitors to the floor. Most nurses averted their eyes when meeting someone in the hallway. This got better as time went on and relationships were established but, for newcomers to the floor, it is very intimidating and unwelcoming. • Lack of information about the hospital expectations, the floor's expectations • One kitchen for several families to use 	<p>Parking at the hospital for tests</p>

If you have had experience with hospice palliative care ~ what is important for the future?

Top three areas of interest were:

1. Trained knowledgeable professionals
2. Support/focus on importance of palliative care
3. Lack of family support/inclusion

Survey participants provided the following examples of what is important for the future:

Trained knowledgeable professionals	Support/focus on importance of palliative care
<ul style="list-style-type: none"> • Specialized training and recruitment of people that have this as their passion • Adequate staffing to provide good care • I feel that there needs to be a person assigned to each family who can help the family navigate the medical system. If I did not know where to go or have my contacts I know my Mom's end of life would not have been as peaceful as it was. The amount of knowledge needed for pain control, symptom control was way beyond what my Dad could have dealt with. Homecare was a great help but they do not have the manpower to work intensively with the family. • Nurse Consultant • More staff • Education for any staff (nurses & physicians) providing palliative care, both in the community and hospital • Staff trained in palliative care • More health care workers trained for this specialized care. There is so much more to it than medicine and bedside manner. • Good basic nursing care • Continuing training of volunteers and healthcare professionals. • Increasing HCP education and awareness of Hospice Palliative Care • Counselling services not available at present and difficult to bring in. Need onsite counsellor/social worker. Not all patients have religious background • Staff training specific to palliative care • Competent and supported coordination to provide patient and family support. • Hospice care workers must be excellent listeners, compassionate, and honest. 	<ul style="list-style-type: none"> • Funding for facilities and staffing to provide palliative care. • More work to make palliative care known in the community--workshops, etc. • Newer more pleasant facility. • Hospice care does not belong in a hospital setting • Greater support from government health resources • Better system for when terminal patients are coming into emergency. They deserve immediate care and comfort in my opinion. • Dedicated facilities for terminal patients • Stand alone facility that isn't clinical • Those who care for end of life people must honour the process of death. • Build up the networks of resources for professionals, caregivers, families closer to us in this region • I believe as well that if someone has a request that would not normally be honoured in the general hospital, they should be allowed. An example would be seeing pets. Just having a little more freedom to do those last few important things. • More equipment

<ul style="list-style-type: none"> • Keep the palliative client and family informed - good communication • Better support for patients and families with coping emotionally • Interdisciplinary rounds • We were privileged to have a fantastic palliative care Dr. who made home visits. Please keep this service in the health care plan and make it worthwhile for palliative care Drs to want to be in that profession. Good Drs. are invaluable. • More consistency with staffing - have the same staff responsible for the patient for the staff's entire rotation. Personal care and consistency would be much easier for the patient if it was provided by the same people or a limited number of staff over the course of several weeks. 	<p>More of exactly what you folks are doing in GPHPCS to help us all out here!!!</p> <p>Research Functioning Hospice's and implement into the new ones being created</p>
<p>Family inclusion</p> <ul style="list-style-type: none"> • If care is going to be patient centered (which includes looking after family needs) I think there should be follow-up for the family. I asked for grief counselling for a family member and was told by the Social Work department that the funding available was for the patient and spouse. • To have shower/laundry facilities for family (important not to be gone for long periods of time)(traveling family members have limited clothing) • Orientation to the hospice room, i.e. how the bed works, what the buttons are for • Orientation for the patient and family to the room and the expected roles (or anticipated roles) for family. Once the patient dons the hospital gown, it's like they become the property of the hospital. Family needs to know that they are welcome to provide the personal care that the patient needs, however they would also need to understand that if they were not able to do this, it is "okay." • Let family members come and go 24/7 (already unofficially in place) • Parking - where do I start? When bringing a palliative patient for tests is close to impossible with only one extra person. You have to know ahead of time how long you are going to be, you have to find a parking spot plus you also have to find a meter that works. 	

<p>Already stressed before you get to the hospital now you are beside yourself because you also have to help the family member who is sick. Why is parking not charge when you leave the spot instead of in advance.</p>	
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If you have had no experience with hospice palliative care ~ list 3 suggestions for the future

The society understands that not everyone has experienced hospice/palliative care yet it is a topic many community members are concerned about and would like to have their comments included so this fourth question was included.

Top three areas of interest were:

1. Trained knowledgeable professionals
2. Medical needs are attended to with dignity
3. Environment

Survey participants provided the following examples of what is important for the future:

<p>Trained Knowledgeable professionals</p> <ul style="list-style-type: none"> • Caring and compassionate staff is number one • Care in a facility designed and staffed to care for only palliative care • Trained knowledgeable staff in provision of end of life care • Nursing support • Nurse Consultant • Excellent, caring people who want to be doing what they're doing - looking after people who are dying • Comfortable & private care space for the dying • Counselling for patient, caregivers, & close family members regarding dying, letting go, grieving • Training for caregivers on how to do it physically and emotionally, avoid burnout • We need a "team" of experts to provide supports to the person who is palliative and their family • Medical personal with palliative care training • Trained health care providers, home support staff, social, spiritual, therapists that work as a team to facilitate proper care. 	<p>The clients medical needs are attended to allowing dignity</p> <ul style="list-style-type: none"> • Pain relief • Pain management • Full Medical care • Medical care • A pain free existence while dying • Pain Management • Access to round the clock medical services • Health care • Quality pain management • Choice to die at home • Home nursing care • Services that enable people to die at home with dignity and gives them access to proper equipment - beds, bathroom aids, etc. • Kindness and dignity to the individual in care • Holistic care not only medical/treatment focused • Nursing staff that is chosen for their empathy with the situation • Care in the home by being able to access equipment to die at home • We need the choice to die at home and receive the supports required • Opportunity for caregivers to take a break & know loved one is in care of a capable person/help at home
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	<ul style="list-style-type: none"> • Assistance with housework when family member is dying at home • The patient or family to be able to choose where their loved one goes to live out their last days • Encouragement of patient autonomy as much as possible • Positive atmosphere where resident can make choices • Patients need to have a one page profile and support plan done for them when entering and updated as needed • Round the clock care • Access to applicable medications • Empathetic staff who are experienced in this area, not just "doing their job". Caring kind people. • Religious beliefs are supported
<p>Environment</p> <ul style="list-style-type: none"> • Comfortable quiet space for family to stay there as well as the patient • Comfortable living space with some accommodation for 1 or more family members to be with you • A hospice facility • A way to make patients as comfortable as possible in a home like setting • We need a hospice that provides a home like atmosphere and is not like a hospital setting • A room that doesn't look like a hospital room but a warm, bright, comfortable place to be • Housing • Comfort • I think that there needs to be rooms available so that family members can stay over if needed • Facilities • A physical environment in which family members can be present with a dying loved one 24 hours a day, unencumbered. i.e. Another bed in the room, small kitchenette, small living area perhaps. • Several private rooms large enough to accommodate family • The family is supported • Comfortable home like environment that encourages family/friend involvement • Room for family members to stay with the person whenever and for however long they wish • A caring, warm environment • Comforts 	<p>Family inclusion</p> <ul style="list-style-type: none"> • Information available when patient is in the hospital before palliative care starts • Family involvement • I think that the patient and their families need to be involved in all aspects of care and decision making around that care <p>Professional support</p> <ul style="list-style-type: none"> • Counselling services for the terminally ill patient and his/her family members. • Client and family counselling • Family support services • Pastoral • Volunteer caregivers • Crisis response team • Support for family members who are losing the loved one • Family support • Social interactions • Counselling for patients & family • Emotional Support • Individual and family counselling to assist with the end of life • Financial support for immediate family member(s) to be near relatives • Education about hospice palliative care and resources available <p>Information on this web page and in print format at senior centres, churches and hospitals.</p>

<ul style="list-style-type: none">• Adequate hospice palliative beds that let people have the comforts of home and respite for caregivers.• Comfortable, home-like surroundings• Home type atmosphere, maybe some kitchen and living room facilities available to share• A comfortable, home-like environment for the patient and his/her family.• Easy access for family, friends & pets	
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Next Steps

The Grande Prairie Hospice Palliative Care Society will use this information to guide their strategic planning process. With the desire to be truly community driven these personal reflections and recommendations will become the foundation of the Society's conversations for how best to move forward.

The survey will continue to be offered on the GPHPCS website. Information collected will be added to our conversations bi-annually as we revisit our strategic planning.