

Honouring Wisdom

A Continuing Conversation About Palliative Care in the NWT

Prepared By:
NWT Seniors' Society



January 16th, 2018

Prepared For:

Department of Health and Social Services
Government of the Northwest Territories

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It is also important to recognize that this report builds off the already incredible work done by the Department of Health and Social Services in the NWT Continuing Care Services Action Plan and its commitment to enhancing culturally appropriate palliative care services. It is our hope that the information contained within this report will act to guide the actions in that plan as they unfold in the future.

Executive Summary

The January 16, 2018 conversation was a continuation of a dialogue from February 2015 and built upon prior work to improve culturally appropriate palliative care in the Northwest Territories (NWT), including work led by the Dene Nation and the Inuvialuit Regional Corporation. Older adults, selected regional healthcare managers and healthcare providers, and invited stakeholders shared their insights and wisdom and listened to diverse perspectives resulting in a balanced, supportive, and respectful conversation.

Respect is at the crux of person-centred care. Given the diversity of culture it is not possible for healthcare providers to know everything about the people they care for. What is necessary is that they are able to provide culturally safe care.

The voices carried insightful messages for frontline healthcare providers, their employers, and the government. At times there was stark contrast in views, which in itself is wisdom. While this document contains important messages for many, the commitment was to derive recommendations for the Department of Health and Social Services from the wisdom shared. The recommendations are meant to guide not only the Department of Health and Social Services and its partners, but also communities as plans and tools are developed, produced, and put into action in a manner that respects the diversity of the NWT.

As participants talked about what would move the palliative care agenda forward, the following themes with implications for recommended action emerged:

- 1) Collaboration, partnership and community engagement;
- 2) Education, training and information;
- 3) Inclusion of traditional practices and customs;
- 4) Person-centred / population-centred planning; and,
- 5) Tools with culturally appropriate messaging.

While diversity gives us much to be proud of it also presents us with a significant challenge as we try to design a palliative care service that is accessible, equitable and culturally and contextually appropriate for the NWT. The palliative approach to care needs to become normalized and embraced as a natural part of living the best life possible. We cannot move forward in the NWT to enhance palliative care services by using one way of knowing, one set of tools or using a unilateral approach.

Communities are vital partners in the palliative approach to care. Given the apparent dependence of communities on government to provide services it will take a concerted effort to shift and reclaim the volunteer spirit that embodies caring communities. Greater involvement of Indigenous governments and agencies as partners could strengthen the community's capacity to provide support needed for people to remain at home and have quality of life. They need to be part of the solution for strengthening and sustaining caring communities.

Looking through the lens of the palliative approach to care means that the conversations need to happen early and involve individuals, their primary care providers, and their families so the expressed wishes and choices for care are known by all who need to know. When the conversations happen early and often, support can be tailored, adjusted as needs change, and continue throughout the life journey and the bereavement period.

Applying this to Indigenous people means widening the lens to accommodate a focus on the collective rather than the individual and broadening the concept of family. It means looking at the cycle of life rather than a continuum from birth to death. It means talking about things in a positive way – about living, not about dying. Accommodating diversity will enable communities to find their own ways of talking about palliative care and advance care planning.

From these themes, several recommendations emerged from participants on the topic of how best to move the palliative care agenda forward in the NWT:

1. Engage people from a cross section of the diverse population in development or adaptation and testing of tools to ensure the words and concepts used are culturally appropriate, user friendly, and provided in a variety of modalities.
2. Use a variety of innovative communication and promotional strategies to make palliative care resources accessible for public and health practitioners as well as ensure awareness of what is available, how to access the materials, how to use the resources and how to provide feedback for continuous improvement.
3. Partner with Indigenous Health and Community Wellness, other government departments and non-governmental organizations for:
 - Cultural safety training;
 - Storytelling preserved on video using NWT voices; and,
 - Support for community capacity-building.
4. Mandate cultural safety training as a compulsory requirement for all health and social services staff to ensure people feel safe accessing palliative care tools and services.
5. Coordinate an interdepartmental review of policies, guidelines, and practices that impact people's ability to age in place so they better support the palliative approach to care and are culturally appropriate.
6. Continue the conversation about palliative care but widen the conversation circle to include Indigenous governments and other stakeholders who can champion and provide leadership for community-based initiatives.
7. Collaborate with the authorities and other partners as necessary to implement, monitor and report on the progress of taking action on these recommendations.

In considering what the next steps should be to enhance palliative care in the NWT, participants also identified the following list of resources and supports that complement and are related to other aspects of the NWT Continuing Care Services Action Plan:

- Expand homecare – nursing, rehab services, home support, after hours services.
- Physicians with expertise for consultation.
- Establish a Palliative Care Team.
- Supports for patients/family caregivers (e.g., respite; support groups, Adult Day Program).
- Equipment to support people to stay at home (including portable ramps).
- Coordination of services with a strong anticipatory planning focus to enable people to age in place.
- Continued development and improvement of facilities for older adults.
- GNWT Corporate responsibility to address barriers and provide support – interdepartmental coordination of policy (e.g. Policy around wait time for housing – when family is ill and have to move to another community).

Participants are passionate about continuing to be a part of the conversation about palliative care, and they express a strong desire to witness change for the better. To feel truly honoured for their wisdom, they need to see they have been heard and that their words will make a change in the way palliative care is viewed and experienced by individuals, families, professional caregivers, and communities across the NWT.

Background and Introduction

Palliative care is not easy to talk about. The NWT Seniors' Society and invited guests started a conversation on this topic in February 2015. At that time participants expressed a need to continue the conversation. With the launch of the NWT Continuing Care Services Action Plan in 2017 an opportunity to do so arose with its commitment to enhancing culturally appropriate palliative care services. The palliative approach to care is best practice in palliative care that involves starting early, having conversations and planning with persons and their families, and respecting the person's values and wishes for care as they journey through a life-limiting condition.

The continuing conversation was held on January 16, 2018. The agenda (Appendix A) was informed by a scan of best practices in palliative care in Canada conducted in late 2017, by the prior conversations in 2015 with older adults and healthcare providers and by prior work done by regional Indigenous groups in the NWT. The NWT Seniors' Society hosted this conversation with a cross section of 30 NWT older adults and stakeholders. Seven healthcare managers from the authorities and two staff from the DHSS were selected to witness the dialogue and participate in the conversation. Older adults, selected regional healthcare managers and healthcare providers, and invited stakeholders shared their insights and diverse perspectives resulting in a balanced, supportive, and respectful conversation.

The objectives of this conversation were:

- 1) To give voice to older adults so that their insights, wisdom and wishes for palliative care become known; and,
- 2) To use the wisdom shared to formulate recommendations to shape the enhancements for palliative care in the NWT.

The recommendations are meant to move us forward so that when tools and products are developed, they are produced and put into action in a manner that respects the diversity (both contextually and culturally) of the NWT. The wisdom shared was profound containing meaningful messages for employing authorities and frontline healthcare providers as well as policy makers and health planners. Participants shared words of wisdom that gave insight into the diversity of the NWT and how people want to be cared for when living with a life-limiting condition. The wisdom shared is honoured in this document.

Method

Large and small focus group discussions were facilitated throughout the day to give voice to those who attended (Appendix B). Plenary discussions were facilitated by Marnie Bell, the lead facilitator. Discussion questions (Appendix C) were designed to encourage participants to share stories, perspectives, insights and thoughts on the focused topics. There were four small discussion groups, each with a diverse mix of older adults, stakeholders and healthcare providers/managers from various regions and different sizes of communities. Each of these focus groups was led by a facilitator who kept conversation focused and flowing. Each group had a dedicated notetaker to ensure that all input was captured.

Shared Wisdom: Summary of the Conversation

This section of the report summarizes the wisdom shared during the plenary and small focus group discussions.

Plenary 1: Setting the Stage for the Conversation

The Department of Health and Social Services highlighted the strategic directions and commitments to action that are driving the initiatives to work with partners, including older adults, to enhance culturally appropriate palliative care in all communities. The 2015 dialogue was recapped so there was a common platform to spring the continuing discussions from.

When participants were asked how they viewed palliative care in general, many viewed it negatively, associating it with end-of-life. They used words such as no hope, fear, denial, depression, separation from family, difficulty navigating the healthcare system and difficult choices with DNR orders. Those who saw palliative care in a more positive light expressed perceptions consistent with current best practice. They talked of comfort, pain management, early conversations, dignity, family and community support, individualized care, cultural food and traditions, receiving palliative care at home, respite for the caregiver, mental health support, acceptance, being able to support people from the beginning and onwards, non-medicalizing the procedures (natural process), consistent medical caregiver team, and a peaceful journey.

Focus Group Topic 1: Getting to Know Me - Respecting Me

Moving from the discussion above, participants went on to view a video called *Embracing Cultural Diversity in Palliative Care* (see Appendix D for list of culturally appropriate resources) before breaking into small groups for discussion. The video explained that showing respect does not mean that you have to understand or agree with another's person's beliefs, wishes or choices; you just need to allow space for the person to do things their own way.

Words of Wisdom:

After contemplating the concept of respect conveyed in the video, participants accepted the concept, acknowledging it as an individualized approach and a cornerstone of culturally appropriate care.

"There are other kinds of respect than what was shown in the video. You must respect what people say they want but you must also respect if they do not want to discuss palliative care or their death." -Group1

Respect is critical. This is their time not ours. -Group 4

In small groups, participants then discussed the following question:

Q. What are your thoughts about this view of respect? How do we go about creating that space for each person on their illness journey?

Words of wisdom were offered for creating that space and align under five themes. Those themes and participant comments relating to them are as follows:

Trust

People may think they don't want to talk about it but with a skilled and trusted support person they may change their mind Those conversations are intimate and are shared with trusted individuals. -Group 1

Create a respectful environment, get to know people, understand people's expectations - create a relationship of trust. -Group 2

Person/Family Focused Approach

Respect by caregivers – this may look different for each person and needs flexibility to allow what people want and need. -Group 2

Be aware of differences and show respect when different views exist. Respect the dying person's wishes but also the family (in bereavement). -Group 3

Advance Care Planning

It is not an Aboriginal value to plan for death: the care provider should not insist on planning if the person does not want to. Let them be. (May help to) have a personal directive, something written if they are willing to write it or have it written for them; some people might like to use a paper or online kit but not everybody would. -Group 1

If families are aware of what a person wants, it makes the end-of-life process easier, including funeral arrangements – less stressful and emotional. -Group 2

Communication Culturally Safe Care

Have continuing open conversation that can progress. People can change their minds.

-Group 2

Don't assume – ASK. Ask them, "Do you want this?" Don't rush to help- ASK; take time to figure out what the person wants. If you don't know – then ASK! Be honest – if it's the "end of life"- tell them. -Group 3

Talking about death is not easy – need support to have these conversations. Open communication is important but some families lack this ability. -Group 2

Differences within the family can be potential for conflict. Communication is important. Patients need to inform their care providers and family members what they want – be their own advocates. -Group 4

Medical staff need to be clear about care options and outcomes so that people can make informed decisions and choose what is important to them e.g. sometimes a person and their family does not understand that further treatments will not be curative. -Group 1

Culturally Safe Care

Realize there are different cultural practices and histories that go with it. In the past people put the "collective" ahead of themselves and would let themselves die if they thought it was for the good of the collective. They would not discuss it with anybody beforehand, as that is not the culture. The dying person needs to have their experience of dying validated and shared by the caregivers even if they don't understand it all, e.g., if a dying person sees a vision, ask them what they see or what it means; don't deny the vision is there. -Group 1

Allow customs of the family – we need to hear and support this is our care process. -Group 2

Recognize there is more than one way. -Group 3

Understand your own biases – cultural safety training is essential. -Group 4

The voices from the northern Indigenous perspective were particularly strong during these conversations. Yet we know there are people from many immigrant cultures and a large contingent of Euro-Canadians also living in the NWT with palliative care needs. Respecting cultural differences will help healthcare providers be aware of cues people may give about readiness to talk and to choose the right words that will open up conversations with people on their journey regardless of what cultural group they associate with

Focus Group Topic 2: Building Caring Communities

Moving naturally from the discussion on respect in palliative care, the topic of caring communities was examined. Compassionate caring communities demonstrate the following characteristics:

- People recognize that we each have a role to play in supporting others in times of health crisis, dying, death and loss; and,
- Individuals are motivated by empathy and kindness to support others through acts of compassion.

There is a need to strengthen community capacity to provide for the many social aspects of care that are critical to the well-being of the patient and their family (e.g., caregiver support groups, companionship for people who are isolated, bereavement support). We heard from previous conversations that these are often lacking, especially in small communities. It takes a community to support a person with a life-limiting illness and also to support their family. In return family and other community caregivers need to be supported so they can sustain their efforts for as long as needed.

Words of Wisdom

In the same small groups, participants were asked the following questions regarding caring communities. Their responses are summarized below.

Q. What does your community need to know about their role as a partner in the care team?

Participants noted that there are conflicts between Indigenous beliefs and views and those of the western healthcare system. Others thought that palliative care is a government responsibility and that as government services become less available they need the caring community to fill the gap. The capacity of communities to support one another has changed as the high cost of living finds many more people working in a wage economy with less time to volunteer and less subsistence living means less ability to share. The lack of volunteerism is complex.

Many people believe “palliative care” means going to the hospital and that is why they don’t want to talk about it – education is needed at the community level so people realize that palliative care is about quality of life; it means supportive care while they are living at home, and that they can often stay home for end-of-life care. -Group 1

Communities need education provided in a variety of ways on the roles and responsibilities of community partners and health care providers, the palliative approach to care, and benefits of community-based care.

More people need to understand it is not just the dying person who needs palliative care. It affects the family and even the whole community. It is painful. Everybody is part of it and needs that care and support.
Group 1

Keeping people at home is not only preferred by most patients but it is also better: the community can come and go to pay respects and offer support without additional travel cost; more people can be accommodated than in a hospital room, and, a more natural end can occur surrounded by family and community.

The community setting has so many benefits; it “keeps you going” and can even prolong life; it supports relationships with youth and grandchildren. Youth are resilient and being near them helps add purpose to an elder’s life. -Group 1

Q. What else besides information do communities need so they can accept and embrace the shared way of supporting and caring for people? Who do you see being involved?

Some felt they are a caring community already because the whole community is there at end-of-life. Yet there was candid expression of lack of volunteers within communities to assist older adults with living prior to the final days. For example, there is reluctance unless there is payment, to mow lawns and shovel snow for older adults. Being able to age in place takes a whole community.

Participants expressed the need for several types of things that would help them to fully reclaim the tradition of caring for one another and enabling people to live the best life possible. These include:

- Human resources such as volunteers, home care and home support in ALL communities, mental health supports, and inter-agency groups.
- Partnerships – for training, supports, planning to fill gaps (e.g. using community wellness plans).
- Volunteer coordination.
- Training tailored to community needs.
- Funding to support and develop community resources including respite for family caregivers.
- Ongoing communication.
- Culturally appropriate, supportive, and flexible policies.
- Intergenerational mentoring.

Q. How do you get community residents to step up and help one another?

Communities need to grow volunteers through training, coordination, and role modeling. Participants suggested that Band Councils and other local structures could be instrumental in finding ways to support quality of life such as snow shoveling, fixing steps and other minor household repairs. This made participants realize that Band Councils and other Indigenous governments should be at the table to be part of the conversation and the solution to enhancing palliative care.

Groups mentioned the need for innovative ways to teach children at a young age what it means to be caring citizens. Community members need to model this citizenship and involve young people in community initiatives where help is provided to those in need. They suggested capitalizing on community service hours needed by high school students, youth organizations, and Community Justice Committees. They also praised intergenerational opportunities where Elders could tell stories to pass on beliefs and traditional practices to young people conveying what it means to be a caring citizen in their culture. Reclaiming attributes of a caring community is integral to strengthening cultural identity and promoting community wellness. These are ways to bring about lasting change; albeit not immediate.

Palliative care involves the community, is part of community wellness and living life fully. Approaching the conversation in this way will raise the profile of the need for community support to start earlier instead of waiting until end-of-life.

Plenary 2: Tools for the Conversation

In 2015 people identified that they needed tools that would help them talk about their wishes for palliative care and make a personal directive. Currently there are few NWT resources but many other provinces and organizations have developed tools that have potential for adaptation.

Moving from the discussion of respect and building caring communities, participants were introduced to examples of tools associated with helping patients and families talk about palliative care.

Participants viewed the video, *The Time is Now: Advance Care Planning for First Nations* (see Appendix D), as an example of what can be developed by Indigenous people for Indigenous people. The video is part of a suite of tools developed through a community driven participatory action research project. The purpose of the toolkit is to explain advance care planning in ways that are culturally appropriate.

Reaction to the video confirmed that storytelling and use of the audio-visual format was a comfortable way to receive information, but participants wanted to see people from the NWT speaking so that the relevance to their own culture was evident.

Susan Ashton, Facilitator, provided background on the development of NWT booklets containing information to help patients/families and primary healthcare providers talk about palliative care. In 2010 these resources were developed using an extensive interview process with over 200 Elders. The Inuvialuit Regional Corporation and the Dene Nation led two separate projects that used the same interview protocol, content outline and subject matter experts. The projects were funded by the Aboriginal Health Transitions Fund.

Focus Group Topic 3: Planning Now for the Future

Participants moved from the plenary back to their small groups to look at the NWT brochure, *Personal Directives: Choosing Now for the Future* (2005) and samples of the NWT booklets talked about by Susan in the plenary. Very few were aware of these resources for planning before you become seriously ill.

Words of Wisdom

Participants were asked the following questions regarding the above tools in their small groups.

Q. What are your general impressions?

Generally, most thought the resources could be a conversation starter and a source of information. There is potential for the resources to be useful for focusing discussion at seniors' groups, community meetings and family meetings. An underlying insight was that the conversation process was more important than the tool itself.

For some it isn't appropriate to talk about death or planning for end-of-life. They want to approach the topic in their own way using words that are culturally appropriate and focused on living rather than dying.

Put the paper away and have the discussion – the conversation is important! Ask “Can we talk about what you want your life to look like?” -Group 2

It is a challenge for some cultures to talk about death or palliative care, e.g., It's unlikely for a Dene leader to stand up and say to a community, “I want to talk about palliative care”. On the other hand, it may be good to have a community-level sharing discussion for the elders so they can learn what is possible and talk about it; and then the community knows what all the elders' wishes are so they don't get families arguing about what they want at the last minute. -Group 1

Q. What are your suggestions for improvement?

The booklets could be improved with updating plus visual and content enhancements. There was division of opinion about the need for materials to be in numerous languages or customized to individual communities and regions. One way of providing information will not meet everybody's needs.

Focus Group Topic 4: Moving Forward in the NWT

From talking about tools relating to palliative care, in their small groups participants began focused discussion enabling consolidation of all that was talked about during the day into next steps.

Words of Wisdom

Participants were asked the following question regarding how best to move the palliative care initiative forward in the NWT:

Q. What needs to happen now? How do we move things forward?

Participants talked about what would move the palliative care agenda forward and shared words of wisdom falling under the five following themes:

1. Collaboration, Partnership and Community Engagement.

Develop plans with support and shared responsibility between different community agencies, governments and family. It takes a community.

Engage Indigenous governments with some prior thought as to the roles/gaps they need to take on to support palliative care. -Group 2

Identify peoples' strengths and utilize them to empower community. -Group 3

2. Education, Training, and Information.

This was viewed as required for health staff, NWT residents, family caregivers, as well as for patients and their families.

Healthcare providers need to understand that palliative care is part of the continuum of care and reflects meeting needs appropriately throughout the lifespan: although the term "palliative care" might be new the practice is part of normal nursing care. -Group 1

Get information out about cycle of life (death is a part of life) and processes to support end-of-life. -Group 2

3. Inclusion of Traditional Practices and Customs.

There should be openness to include traditional customs and practices if a person wishes. Consider ways to fit western culture and Indigenous culture together.

Need to be clear that culture is about personal choice as well as community history. -Group 1

Build bridges – native/non-native; urban/rural – we are not all the same but we can help each other. -Group 1

4. Person-Centred Planning.

Begin by asking people what they want by breaking down comprehensive questions into simple specific questions. Tools to guide this conversation should be incorporated into existing guidebooks.

Think of the person, not the process. -Group 3

Tools that “build up” to goals of care discussion, e.g., getting to know you, what do you want your life to look like, ...then, ...do you want resuscitation?” -Group 2

5. Tools with Culturally Appropriate Messaging.

Culturally appropriate tools require universal messaging that can be translated into local languages for community radio and “learning language” programs. The community can become more involved in helping to spread the word about the palliative approach to care but they need videos, print materials, prepared presentations for community workshops/presentations to increase awareness and knowledge.

In addition to these themes, participants identified several next steps that support other key activities in the Continuing Care Services Action Plan. These are listed in Appendix E. All of this information has been incorporated in the recommendations for moving forward with the palliative care agenda at the end of this report.

Discussion

We cannot move forward in the NWT to enhance palliative care services by using one way of knowing, one set of tools, or using a unilateral approach. Given the diversity of cultures in the NWT, respect is at the crux of person-centered palliative care. This presents a significant challenge in designing a palliative care service that is accessible, equitable, and culturally and contextually appropriate for the NWT. While it may not be possible for health care providers to know everything about the people they care for it is necessary that they are able to provide culturally safe care in some way, shape, or form. The palliative approach to care needs to become normalized and embraced as a natural part of living the best life possible.

Further, from participant discussion it is clear that looking through the lens of the palliative approach to care as described above means that conversations need to happen early and involve patients, their primary care providers, and their families so the expressed wishes and choices for care are known by all who need to know. When the conversations happen early and often, the support can be tailored, adjusted as needs change, and continue throughout the illness journey and the bereavement period.

Based on the wisdom shared, applying this lens to Indigenous people means widening the lens to accommodate a focus on the collective rather than the individual and broadening the concept of family. It means looking at the cycle of life rather than a continuum from birth to death. It means talking about things in a positive way – about living, not about dying.

Communities are vital partners in this palliative approach to care. Given the apparent dependence of communities on government to provide services, it will take a concerted effort to shift and reclaim the volunteer spirit that embodies caring communities. Greater involvement of Indigenous governments and agencies as partners could strengthen the community's capacity to provide support needed for people to remain at home and have quality of life. Accommodating diversity will enable communities to find their own ways of talking about palliative care and advance care planning. There is more than one way of thinking and talking about palliative care.

With that idea in mind, several recommendations emerged from participants on the topic of how best to move the palliative care agenda forward in the NWT

1. Engage people from a cross section of the diverse population in development or adaptation and testing of tools to ensure the words and concepts used are culturally appropriate, user friendly, and provided in a variety of modalities.
2. Use a variety of innovative communication and promotional strategies to make palliative care resources accessible for public and health practitioners as well as ensure awareness of what is available, how to access the materials, how to use the resources and how to provide feedback for continuous improvement.
3. Partner with Indigenous Health and Community Wellness, other government departments and non-governmental organizations for:
 - Cultural safety training;
 - Storytelling preserved on video using NWT voices; and,
 - Support for community capacity-building.

4. Mandate cultural safety training as a compulsory requirement for all health and social services staff to ensure people feel safe accessing palliative care tools and services.
5. Coordinate an interdepartmental review of policies, guidelines, and practices that impact people's ability to age in place so they better support the palliative approach to care and are culturally appropriate.
6. Continue the conversation about palliative care but widen the conversation circle to include Indigenous governments and other stakeholders who can champion and provide leadership for community-based initiatives.
7. Collaborate with the authorities and other partners as necessary to implement, monitor and report on the progress of taking action on these recommendations.

Participants are passionate about continuing to be a part of the conversation about palliative care, and they express a strong desire to witness change for the better. To feel truly honoured for their wisdom, they need to see they have been heard and that their words will make a change in the way palliative care is viewed and experienced by individuals, families, professional caregivers, and communities across the NWT.

Talking is important and we need to continue these conversations about palliative care. Is there a willingness to move to action?

Appendix A: Agenda

Getting to Know Me: Aging in Place: Agenda for A Continuing Conversation about Palliative Care

January 16, 2018

Location: Nunasi Building. 2nd floor, Genesis Room

5109 48th Street, Yellowknife

- 08:30 – 0900** **Opening Prayer – Elder**
Housekeeping & Instructions for the Day – Marnie Bell
Welcome & Objectives for the Day– Barb Hood
- 09:00-09:45** **Setting the stage for the conversation**, large group discussion (Genesis Room) – Marnie Bell, facilitator
- 09:45-10:00** **Getting to Know Me**, (Genesis Room)
Video “Embracing Cultural Diversity in Palliative Care”- introduced by Marnie Bell
- 10:00-10:30** **Focus Group Breakout Discussion** (Facilitators: Marnie Bell, Susan Ashton, Barb Hood, Mike Prowse) - **Topic 1: Respecting Me**
- 10:30-10:45** **Break**
- 10:45– 11:30** **Focus Group Breakout Discussion - Topic 2: Building Caring Communities**
- 11:30- 1200** **The Power of What We Heard –** large group discussion (Genesis Room); Reporting back on key points from Topic 1 & 2
- 12:00-1:00** **Lunch Break** (lunch catered on site)
- 1:00- 1:30** **Presentation of Examples of NWT Culturally Adapted Tools** (Genesis Room)- Susan Ashton
Video: *The Time is Now: Advance Care Planning for First Nations* – introduced by Marnie Bell
Follow-Up Large group discussion - Tools
- 1:30-2:15** **Focus Group Breakout Discussion - Topic 3: Planning now for the Future – impressions of existing tools**
- 2:15-2:30** **Break**
- 2:30-3:15** **Focus Group Breakout Discussion - Topic 4: Moving Forward in the NWT**
- 3:15-3:30** **Break**
- 3:30-4:00** **Words of Wisdom for GNWT**, large group discussion (Genesis Room); Reporting back on key points from Topic 3 & 4
- 4:00-4:30** **Closing Large Group Discussion - Marnie Bell, facilitator**
- 4:30** **Closing Prayer – Elder**

Appendix B: Attendees

Facilitators

Name	Community	Position	Organization
Barb Hood	Yellowknife	Executive Director	NWT Seniors' Society
Mike Prowse	Yellowknife	Program Coordinator	NWT Seniors' Society
Susan Ashton	Yellowknife	Consultant	Ashton Consulting
Marnie Bell	Yellowknife	Consultant	Marnie Bell Consulting

Note Takers

Name	Community	Position	Organization
Andrea Booth	Yellowknife	Senior Nursing Consultant, Homecare	DHSS
Lisa Rayner	Yellowknife	Territorial Manager, Continuing Care	NTHSSA
Sandra Mann	Yellowknife	Manager, Seniors Affairs	DHSS
Victorine Lafferty	Yellowknife	Director, Seniors & Continuing Care	DHSS

Focus Group Participants

Name	Community	Position	Organization
Mary Pat Short	Fort Smith	President	NWT Seniors' Society
Leon Peterson	Fort Smith	Past President	NWT Seniors' Society
Alphonsine McNeely	Fort Good Hope	Vice President	NWT Seniors' Society
Tom Makepeace	Hay River	Secretary	NWT Seniors' Society
Sam Gargan	Fort Providence	Board Member	NWT Seniors' Society
Mavis Klaus	Fort Resolution	Board Member	NWT Seniors' Society
Terry Villeneuve	Fort Resolution	Alternate Board member	NWT Seniors' Society
Lorell Gauthier	Fort Smith	Alternate Board Member	NWT Seniors' Society
Pamela Murray	Yellowknife	Advocacy Committee	YK Seniors' Society
Florence Barnaby	Fort Good Hope	Alternate Board Member	NWT Seniors' Society
Margaret Rose Elleze	Fort Providence	Alternate Board Member	NWT Seniors' Society
Elizabeth Kunnizzie	Inuvik	Alternate Board Member	NWT Seniors' Society
Pat Burnstead	Hay River	Alternate Board Member	NWT Seniors' Society
Bea Campbell	Fort Smith	Past Board Member	NWT Seniors' Society
Martha MacLellan	Yellowknife	Regional Lead	Alberta and NWT Alzheimer Society
Wanda Roberts	Yellowknife	Senior Instructor/ Personal Support Worker	Aurora College
Margaret Marshall	Yellowknife	Healthcare Provider (retired)	
Samantha Thomas	Yellowknife	Executive Director	Status of Women
Janice McKenna	Yellowknife	Director	McKenna Funeral Home
Audrey Henderson	Yellowknife	Director	McKenna Funeral Home
Catherine Dixon	Yellowknife	Cancer Care Coordinator	Stanton Territorial Hospital
Nancy Cymbalisty	Yellowknife	Healthcare Provider	
Fernanda Martins	Yellowknife	Policy Analyst	Canadian Cancer Society
Jennifer Picek	Inuvik	Manager, Continuing Care	NTHSSA – Beaufort Delta
Malerie Norwegian	Fort Simpson	Nurse-in-Charge, LTC	NTHSSA -Dehcho
Lisa Saunders	Fort Smith	Manager, Continuing Care	NTHSSA- Fort Smith

Name	Community	Position	Organization
Karin Bucher	Yellowknife	Manager, Yellowknife Homecare	NTHSSA - Yellowknife
Ashley Crump	Yellowknife	RN, Extended Care	NTHSSA - Stanton
Mary Davies	Hay River	Manager, Continuing Care	HRHSSA
Daniel Gunn	Behchoko	Healthcare Provider	Tlicho Community Services Agency
Annie Goose	Uluhaktok	Regional Wellness Council member	RWC- Beaufort Delta
Sandra J. Whiteman	Norman Wells	Regional Wellness Council member	RWC - Sahtu
Raymond Michaud	Fort Simpson	Regional Wellness Council member	RWC - Dehcho
Gloria Villebrun	Fort Smith	Regional Wellness Council member	RWC - Fort Smith
Karen Hamre	Yellowknife	Regional Wellness Council member	RWC - Yellowknife
Dinah Carnogursky	Hay River	Regional Wellness Council member	RWC – Hay River
Ted Blondin	Behchoko	Regional Wellness Council member	RWC - Tlicho
Sheena Peter	Yellowknife	Senior Nursing Consultant, Primary Health Care	DHSS
Karen Blondin Hall	Yellowknife	Senior Advisor, Indigenous Health	DHSS

Mental Health Support

Name	Community	Position	Organization
Mark Fraser	Yellowknife	Mental Health & Addictions Specialist	DHSS
Andrea Brown	Yellowknife	Territorial Manager, Mental Health & Addictions	NTHSSA

Appendix C: Focus Group Questions

Focus Group 1: Respecting Me

In the video, she said: “Respect is about allowing a person the space to do things in their own way regardless of your own personal beliefs or biases.”

Q. What are your thoughts about this view of respect? How do we go about creating that space for each person on their illness journey?

Focus Group 2: Building Caring Communities

We hear that community support is very important when people are going through a difficult time. We have also heard that most people like to remain at home or in their home community when they are ill so they can be cared for in familiar surroundings and have their loved ones around them. For people to remain at home for as long as possible, it takes the community and the health care providers working together to provide care for the patient and their family. We heard from our previous conversation that there is a lack of support groups and capacity, especially in small communities, to offer support to family caregivers.

Q. What does your community need to know about their role as a partner in the care team? What else besides information do communities need so they can accept and embrace the shared way of supporting and caring for people? Who do you see being involved? How do they get involved?

Focus Group 3: Planning Now for the Future – Tools for talking about what is important before you get seriously ill.

Look at these resources: NWT booklets about palliative care for patients, families and communities and education guides for primary care providers; Brochure *Personal Directive: Choosing Now for the Future*

Q. Have you ever seen these resources? Have you used them? If so, tell us about your experience in using them? What are your general impressions?

Focus Group 4 : Moving Forward in the NWT

What we have been talking about is “living the best life possible” when you have a life-limiting condition, one that cannot be cured. It means not needing to suffer or be in pain and being supported to live and enjoy quality of life along the illness journey.

Q. What needs to happen now? How do we move things forward?

Appendix D: Culturally Appropriate Resources and Tools

The resources and tools were developed by studies, initiatives and projects in Canada. They are products of best practice that have been used and proven beneficial for users. Many could be either adopted or adapted with the input of NWT traditional knowledge holders.

Tools for the Journey: Palliative Care in First Nations, Inuit and Metis Communities

https://www.cancercare.on.ca/toolbox/pctoolkit_aboriginal/

The toolkit consists of a series of pamphlets and supplementary information, and is based on input from First Nations, Inuit and Métis people on what palliative care means to them and what kind of information and support they need relative to palliative care. These conversations took place in a series of focus groups and interviews held across Ontario in 2013–2014.

Improving End-of-Life Care for First Nations Communities

<http://eolfn.lakeheadu.ca/project-results/culturally-appropriate-resources>

Improving End-of-Life Care in First Nations Communities was a successful 5-year (2010-2015) participatory action research project with four First Nations communities in Ontario and Manitoba designed to build community capacity. Community capacity building resources were developed and in partnership with the Canadian Hospice Palliative Care Association/The Way Forward and the Quality End-of-life Care Coalition of Canada a culturally appropriate suite of advance care planning tools and educational resources were developed and evaluated.

- *Developing Palliative Care Programs in First Nations Communities: A Workbook* - Workbook for First Nations communities to plan palliative care programs. Includes 40 research informed tools. Used to build community capacity in the research project led by the Centre for Education and Research on Aging and Health at Lakehead University.
- *Supporting the Development of Palliative Care Programs in First Nations Communities: A guide for External Partners* – A guide to be used by external partners to support First Nations communities who are developing palliative care programs.
- *The Time is Now: Advance Care Planning for First Nations* – a video about advance care planning for community awareness
- *Advance Care Planning Tools* - culturally appropriate pamphlets and posters, guidelines for a community ACP workshop including a presentation with facilitators guide.

Living My Culture

<http://livingmyculture.ca/development-team>

A website that contains videos from two projects funded by the Canadian Partnership Against Cancer. The **Living My Culture** project engaged people from 8 cultures to share their stories about the intersection of culture and advanced illness, end-of-life and grief. The **Indigenous Voices: Stories of Serious Illness and Grief** project interviewed First Nations Inuit and Métis from across the country about experiences, lessons learned and words of wisdom for those travelling a similar path.

Completing the Circle of Life

<http://www.aboriginalendoflifecare.com/>

This Community Action Research project undertaken by the First Nations University, Saskatchewan, developed educational products including several videos both for healthcare providers and for aboriginal families designed to increase awareness of cultural differences.

Inuusinni Aqqusaaqtara – My Journey

<http://pauktuutit.ca/cancerpartnering/>

This project of the Pauktuutit Inuit Women of Canada developed tools and resources to support Inuit patients, cancer survivors, family members and health care professionals, including a glossary, a booklet about cancer, a journal to write about your personal cancer journey and a video “One Woman’s Journey”, the story of a survivor of breast cancer. Written materials are available in English, Inuktitut, Nunavik and Inuinnaqtun.

Canadian Virtual Hospice

http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx

Excellent evidence-based repository of research, best practices, clinical practice tools, videos, “Ask the Professional”, listing of answered questions. The Canadian Virtual Hospice provides support and personalized information about palliative and end-of-life care to patients, family members, health care providers, researchers and educators. Several videos housed here about aboriginal people and palliative care could be useful to stimulate conversations but should be vetted by local NWT Elders before using.

Videos: By Carrie Bourassa, PhD, First Nations University of Canada

- *Common questions health providers ask about end of life for Aboriginal people*
- *Accommodating cultural diversity*
- *Roles of elders at end of life*
- *Why are there 40 people in the room?*
- *Grief and aboriginal people*
- *The importance of family and community*

Video by Canadian Virtual Hospice featuring an First Nations (Cree) RN who cared for her grandfather at end of life.

- *The privilege of caring – potential conversation starter for community capacity building.*

Appendix E: Expanded Resources and Supports

In considering what the next steps should be to enhance palliative care in the NWT, participants also identified the following list of resources and supports that complement and are related to other aspects of the NWT Continuing Care Services Action Plan.

- Expand homecare – nursing, rehab services, home support, after hours services.
- Physicians with expertise for consultation.
- Establish a Palliative Care Team.
- Supports for patients/family caregivers (e.g., respite; support groups, Adult Day Program).
- Equipment to support people to stay at home (including portable ramps).
- Coordination of services with a strong anticipatory planning focus to enable people to age in place.
- Continued development and improvement of facilities for older adults.
- GNWT Corporate responsibility to address barriers and provide support – interdepartmental coordination of policy (e.g. Policy around wait time for housing – when family is ill and have to move to another community).