

“Let the Tree Grow, Not Cancer”

Report on the Fort Good Hope Community Cancer Sharing Session

June 18 and 19, 2012

Fort Good Hope, Northwest Territories



Author: The Saint Elizabeth First Nations, Inuit, and Métis Program



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Kispin ki nitawih̄tīn ā nihiyawih̄k ōma ācimōwin, tipwēsīnēn.

Cree

ᑭerih̄tī'is dēne sūfiné yati t'a huts'elkēr xa beyéyati theᑭat'e, nuwe ts'ēn yólti.

Chipewyan

If you would like this information in another official language, call us.

English

Si vous voulez ces renseignements en français, contactez-nous.

Français

Jii gwandak izhii ginjik vat'atr'ijāhch'uu zhīt yinothān jī', diits'āt ginohknii.

Gwich'in

Hapkua titiqqat pijumagupkit Inuinnaqtun, uvaptinnut hivajarlutit.

Inuinnaqtun

ᑕᑭᑭᑦ ᑕᑭᑭᑦ ᑕᑭᑭᑦ ᑕᑭᑭᑦ ᑕᑭᑭᑦ ᑕᑭᑭᑦ ᑕᑭᑭᑦ ᑕᑭᑭᑦ.

Inuktitut

UVANITTUAQ ILITCHURISUKUPKU INUVIALUKTUN, QUQUAQLUTA.

Inuvialuktun

K'ēhshó got'ine xadá k'ē hederi wēdih̄tī'ē yeriniwē nídé dúle.

North Slavey

Edi gondi dehgéh got'ie zhatie k'ēē edat'ēh enahddhē nide.

South Slavey

T̄h̄ch̄o yati k'ēē dē wegodīl wek'ēhoiz̄o nēw̄o dē, gots'ō goahde.

T̄h̄ch̄o

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Dedications

This report on the Fort Good Hope Cancer Sharing Session is dedicated to the people of Fort Good Hope and the individuals and families affected by cancer. In the words of one session participant *“Together we can beat cancer!”*

Acknowledgements

The Saint Elizabeth First Nations, Inuit and Métis Program would like to acknowledge the presence and role of the Elders and special mention of Laura Tobac and Lucy Jackson who also provided interpreter services. We would also like to thank Vicky Orlas and Barthy Kochilly, both of whom are cancer survivors, for their thoughtful contributions throughout the day-and-a-half sharing session.

Acknowledgement and recognition is also given to Donna Shae, Acting Band Manager, who assisted in the coordination of the sharing session at the community level.



Barthy Kochilly

A special acknowledgement and thank you is given to Barthy. Barthy is a recent cancer survivor who provided the title “Let the tree grow, not cancer” for this report during the building of the Tree of Hope activity on the last day of the cancer sharing session.

Introduction

This report represents findings of the cancer sharing session held in Fort Good Hope, Northwest Territories on June 18 and 19, 2012. This session focused on facilitating open dialogue among the community members where they could voice their concerns about community cancer rates and identify what opportunities exist to support and enhance the health of their community. The sharing session encouraged participants to talk about their concerns around the rates of cancer within their community and participate in sharing session activities to identify the gaps and challenges in the current cancer system. The sharing session also provided opportunities for participants to highlight what is working well in their community and what could be done to address current gaps and challenges. Through this process, recommendations were generated to facilitate positive action and change for the community of Fort Good Hope. The session was held in response to the community's request and was funded by the Government of the Northwest Territories (GNWT).

The cancer sharing session in Fort Good Hope was facilitated by members Tracy Scott, Doris Warner and Melissa Spence of the Saint Elizabeth First Nations, Inuit, and Métis Program with co-facilitator supports provided by Patricia Kyle, CEO of Sahtu Health and Social Services Authority and Sabrina Broadhead from the GNWT Department of Health and Social Services (DHSS).

Saint Elizabeth is a social enterprise dedicated to the health of people and communities and is involved in virtually every aspect of health care – from system design to service delivery. Saint Elizabeth is continually looking for ways to impact change in order to create a wiser, more equitable and humane health care system. Our vision is to 'Honour the Human Face of Health Care' and our dedicated First Nations, Inuit and Métis Program is a key initiative that demonstrates how we live out our vision. Through partnership and collaboration, the program works to enhance and support the capacity of First Nations, Inuit, and Métis (FNIM) communities to understand and solve complex health care issues, improve access and address barriers to care. Further information on the Saint Elizabeth First Nations, Inuit, and Métis Program can be found at: <http://fnim.atyourside.ca/about-us>

The session report provides an overview of the purpose of the sharing session, the types of activities participants engaged in during the day-and-a-half session, and the results of their discussions.

Overview of the Cancer Sharing Session

Sharing Session

The premise behind the sharing session approach is to create an environment for dialogue and open discussions on cancer in a manner that is culturally safe and meaningful for the participants. The sharing session was designed to foster open communication that identifies not only the challenges but also the opportunities for addressing or overcoming these barriers. With the firm belief that the knowledge is in the room, the role of the facilitators was to act as a conduit in bringing the information together in a way that was respectful to all sharing session participants.

An important aspect of the sharing session was time allotted to have fun. This was accomplished through games and energizers throughout the day and a half that got participants moving and laughing. The purpose of these activities was to bring joy back into the room and to help keep participants motivated and re-energized to push on through the difficult discussions.



Sharing sessions are a collective effort and require a team that includes facilitators, coordinators and community champions. The coordinators helped to get the logistics of the day in place. This included any necessary booking of the venue, supporting the facilitators' travel, and nutritious meals and snacks and beverages during the sharing session. The role of the community champions was to get the word out at the community level about the session, and to encourage and promote participation. The community champions also assisted the facilitators and coordinators in understanding any community protocols around engagement. This included the involvement of Leadership and Elders, who played a vital role during the sharing session by providing support and guidance throughout the session.

The sharing session can be thought of as a community of learning that brings together individuals that share a common interest or passion, such as cancer awareness and prevention. This is a form of knowledge exchange that comes very naturally to First Nations communities.

"We don't always know how to give hope or what to say but by participating in a workshop like this we are learning first hand, which is a far better way to do this then reading a paper. We've always done this, sit together and found solutions. With cancer you can't do it by yourself!" (Session Participant)

The Fort Good Hope Cancer Sharing Session



Participants

Participants attending the cancer sharing session included community members of all ages, Leadership, community health care providers (Home Support Workers and Nurses), caregivers, Band staff, Land Corporation staff and cancer survivors from the community of Fort Good Hope. Participant attendance throughout the day-and-a-half sharing session fluctuated from approximately 32-60 participants.

Purpose

The purpose of the Fort Good Hope Cancer Sharing Session was to involve community members, health care providers, caregivers, cancer survivors and community Leadership in sharing their knowledge through stories and experiences. Participants from Fort Good Hope gathered together for this cancer sharing session at the Fort Good Hope Band Council Hall. Participants were eager and willing to share their knowledge and concerns about cancer in their community.

Agenda and Activities

The cancer sharing session started with a community supper, where participants were greeted at the door and directed to a table dedicated and stocked with items to decorate name tags. Following the dinner, a sharing circle was held for introductions of all participants, facilitators and presenter Dr. Corriveau, Chief Public Health Officer (CPHO). The next activity was the discussion of participant expectations for the sharing session and the day adjourned with discussions on what a healthy community looks like and a final sharing circle of reflections from the evening's activities.

On the second day the participants were once again greeted and the day started with a sharing circle for reflections on the activities the evening before. Next, the community perceptions of cancer were discussed followed by presentations on "What is cancer?" as well as cancer statistics for the community, region, and territory. The afternoon continued with discussion on the community's current cancer pathway for prevention – screening – diagnosis – treatment – survivorship/palliation. The participants identified the challenges and what the community can do (opportunities, solutions) along the cancer pathway. The sharing session concluded with the development of a **Tree of Hope** and a final sharing circle was held where participants provided reflections on the day-and-a-half cancer sharing session. The cancer sharing session agenda is located in **Appendix A**.

The cancer sharing session in Fort Good Hope included break-out groups and sharing circles as well as fun energizers and games that were both structured and lighthearted. Meals, snacks and beverages were also provided.



Expectations

At the start of the session participants were invited to share their expectations for the day-and-a-half gathering. During the introductions participants were asked to identify their favourite season. The participants were then asked to break up into those seasons: spring, summer, fall and winter, to identify their expectations of the cancer sharing session. The groups outlined their expectations on flip chart paper and reported their expectations back to the larger group.

A frequently cited expectation was to discuss the concerns about cancer rates within the community.

“We have had twelve deaths in the community within the past two years...we just lost one two days ago. We need to do something; too many loved ones are dying from this cancer!” (Session Participant)

Participants also expressed a strong interest in discussing their concerns about environmental pollutants such as asbestos and water contaminants, particularly those that affect traditional foods and have an impact on cancer incidence. Additionally, participants wanted to talk about the importance of cancer prevention and early detection, as well as palliative care.

It was evident from the roundtable introductions that all of the participants' lives had been touched by cancer. During the discussions on expectations, participants expressed the importance of gathering to talk about cancer.

"We've always done this, sit together and found solutions." (Session Participant)

Healthy Community

On the first day, participants were broken up into groups based on the four seasons and each assigned with an aspect of well-being (Spring - Physical, Summer - Mental, Fall - Emotional and Winter - Spiritual).



The groups' task was to brainstorm what makes a healthy community according to the four dimensions, and discussions were recorded on flip chart paper. The following are the notes from these discussions:

Physical

- Expeditions
- Lots of laughter
- Exercise
- Sauna
- Recreation Centre
- Hiking
- Canoeing

- Walking groups
- Meditating
- Local foods
- Drum dancing
- Singing
- Healthy diet
- Support meetings
- Cultural camps
- Friendship tournaments
- Family activities
- Communications skills
- Friends, socializing
- Change of scenery
- Generation gap bridging
- Men's group, hosting more men's activities like a grooming spa
- Spa night
- Healthy cooking lessons
- Drink water – lots
- Play games – healthy
- Movie night with popcorn
- Adventuring - traditional medicine
- Berry picking
- Gardening and plant flowers
- Build a fountain of hope, love, peace

Mental

- Confident – we've educated ourselves about cancer
- We care – about each other
- We trust our health care providers
- We have good coping skills – less stress for everyone!
- We are positive
- We take care of ourselves, we do not expect others to look after us
- We are proud of who we are
- We do not judge each other
- We accept differences

Emotional

- Financial security (no worries)
- Places to go for support (both caregivers and patients)
- Have dealt with residential school syndrome (tradition, values, beliefs)
- Clearly defined roles on how to support others who are sick
- Understanding of each other, in offering and receiving help
- Respect individual and family decisions

- Know/understand how to take cancer medication/take care of self and follow instructions from the doctor
- Emotional disturbance reduction

Spiritual

- More going out on the land (spiritual gathering)
- Traditional medicines
- Drum dance and feast
- Support group meetings
- Elders gathering
- Community involvement
- More gatherings (healing workshops, AA, round ups)
- Cultural Teachings (language)
- Church
- Woodblock Festival, Midway Lake Festival (festival outside of Fort McPherson), hand-games, square dance, Dene games
- More cultural games
- Walking traditional trails, relearning the ways of our ancestors

The children were also asked to share what they believe makes a healthy community. They were provided with all the tools necessary to create a mural that depicts what makes a healthy community. They did so with enthusiasm, laughter and singing.



The completed mural is pictured below. The drawing represented:

- Love (indicated by the word and hearts)
- Northern Store in the community
- Castles and nice houses
- Sun and sunshine
- Lots of butterflies
- A bed to sleep in

- Healthy food (oranges, tomatoes, strawberries etc.)
- Teacher (Miss Gennie)
- Money
- Representations of physical activities (bikes, walking)
- Music (One Direction Band)
- Healthy water
- Green trees
- Bugs

The children presented their mural back to the adult participants later in the evening, receiving great applause from the community.



Community Perceptions of Cancer

The cancer pathway can be complicated and is complex. Identifying the community norms or perceptions of cancer is a starting point in discussing the barriers experienced in the cancer pathway.

In the discussion of community perceptions, participants shared that there is a community-wide sense of fear, anger, hopelessness and the grieving of the loss of loved ones and community members from cancer. Some expressed concerns that cancer is caused primarily by environmental changes and the effects of contamination like mining, on the water, wildlife and fish that the people consume. Other causes the participants attributed to the increased risk of cancer were smoking and unhealthy thinking patterns and lifestyles. Other participants shared there was a lack of knowledge of how to give comfort

to community members living with cancer and their families as well as when there is a death in the community from cancer.

Participants shared about the issues stemming from the history and legacy of residential schools and the negative impact on individuals, families and community. The issues included the loss of traditional values of love, caring and respect for one another and community cohesiveness resulting in a pervasive sense of hopelessness and not being in control of their health and well-being that continues to significantly impact the peoples' ability to proactively address their health and well-being.

The majority of the perceptions expressed were related to ways to prevent cancer through positive thinking and returning to more traditional activities and lifestyle. Traditional activities and lifestyle examples included bringing back traditions of returning to the land for community celebrations and working with the earth (gardening, trapping, fishing, etc.). There were many who expressed the need to bring back the traditional way of living by loving, caring and respecting one another and to teach the younger generation these values.

"We need to learn from one another". (Session Participant)

Participants also discussed the importance of empowerment through self-advocacy:

"With every sickness we get we have to fight for ourselves". (Session Participant)

Although the activity was about community perceptions, cancer community solutions were already being discussed. This confirmed the thinking that the answers were already in the room.

The following are a culmination of the communities' perceptions of cancer documented from the large group sharing circle on flip chart paper and reported:

- Cancer comes from the water, fish
- Comes from smoking
- Getting stronger (cancer)
- When will it be our turn?
- Piece of us is gone when someone dies of cancer
- Lot of different cancers
- No fun at all

- Every sickness we get we have to fight for ourselves
- Took care of myself (cancer survivor)
- Take care of my mind and body
- Stress
- Not taking care of un-dealt with matters in their life
- Difficult to go to my Dad, he died of cancer
- I went to workshops. That is how I learned about trauma, life skills and who I am.
- If you worry too much it weakens your immune system. People don't know how to de-stress. Now I read my Bible. I know who I am. Through prayers we become who he (God) made us to be.
- We are important and need to care for ourselves. Laugh, cry with them. Wave at them.
- We are not perfect
- Difficult to say "sorry", we weren't taught how
- Know and open our lines with God. He gives me strength and teaches me.
- When I think about cancer:
 - Brings me to self-love and care and taking care of myself
- Stress - diseases come from this. How we think and feel. Body reacts to how we think and feel.
- Stressors: job, people, residential school, bills, can feel it on our body, we tense up, not breathing. Releasing stress like go to the bush, scream, and cry to let it out.
- Diet - foods we eat and put into our bodies
- Concerned about our water
- Need to reprogram this brain to think positive
- Things don't happen overnight. Good to hear about this (sharing session) in the community.
- Cancer is very important. We need research, studies on the water, fish, animals.
- Need to find out where it (cancer) is coming from
- Very hard, we shut out our feelings
- Activity around Fort Nelson puts contaminants on the land
- Fort McMurray - people are seeing fish without tails, sores on the fish, fish with no fins, fish with ½ a head and a beaver with two heads
- People need to protect the land
- Money is first, not the people and the land, we need to find a balance (referring to mining)
- We know you're hurting (referring to people with cancer and the survivors) but we are lost and don't know how to comfort!
- I suffer from anxiety, can't sleep. We need to find ways to help others.
- As a leader sometimes you don't see what we put up with. Hurt, stress, anger, losing people. We depend on prayer to get us through another day.
- Residential school, we never dealt with. Young people need to know the effects where traditional values went out the door.
- Need to learn from one another
- Lot of different things we learned (young people)
 - Smoking
 - Learn things on our own

- Teaching young people
 - Water, how to protect their bodies
 - Taking vitamins
- Stress from past issues
 - Never talked about
 - Had therapy sessions
- Survival, we need to learn about the animals, traditional medicines
- Lots of people are dying
 - Don't know how to act, what to say! Encouragement
 - Felt kind of lost
- Learned on my own to share:
 - How we grew up together.
Stories
 - Try not to think negatively
 - Releasing secrets to my family.
What I've seen, experienced,
what I learned.
- Teach my children and love them the way I never got, how to eat regularly
- Keep praying
- More processed foods, moving away from our traditional diet

Cancer Education and Presentations

Presentations were conducted by the sharing session facilitator Doris Warner, Saint Elizabeth First Nations, Inuit and Métis Program, on the basics of cancer and Dr. André Corriveau (CPHO), Northwest Territories.



The following topics were presented by Doris Warner to the sharing session participants:

- Understanding cancer
- What Causes cancer?
- Types of cancer
- Risk Factors of cancer
- Warning Signs
- Cancer Prevention
- Early Detection and Screening
- Diagnosis
- Treatment
- Survivorship
- Palliation/End-of-Life



Dr. Corriveau presented on the following topics:

- What is cancer?
- NWT Cancer Registry
- Cancer trends in the NWT
- Sahtu HSSA and Fort Good Hope cancer rates
- Comparison of cancers in Fort Good Hope to NWT
- Summary

During the presentation the sharing session participants had many questions and they are outlined below along with key messages and answers.

Question: What are the cancer rates in Fort Good Hope (FGH)? How do our rates compare to other communities in the Sahtu region and the Northwest Territories?

Answer: In the NWT, Sahtu and FGH there has been a steady rise in the rates for new cancer diagnoses. In the NWT, this has increased from almost two to three per 1,000 population.

Typically FGH experiences one to two cancers per year. Between 2002 and 2004, it had three to four cancers diagnosed. After 2004, the number returned back to normal. An increase of one to two cancers can increase the rates by a lot. This is because of the small population numbers. Preliminary data indicate that there were three cancers diagnosed in 2010 and two in 2011 in FGH. Due to fluctuation of the rates (i.e. small numbers), we cannot actually say that the rates in FGH are significantly different from the NWT or Sahtu.

The average age at death has increased by more than ten years over the last 3 decades. On average, people are living longer. The percentage of deaths among infants has decreased over the last three decades with deaths due to infections and injuries/poisoning decreasing. The major leading causes of death are diseases related to age. Cancer is now the leading cause of death followed by diseases of the circulatory system.

Over 50% of cancers diagnosed in NWT are one of the 'top four' which are colorectal, breast, lung and prostate. Almost three quarters of the cancers in Fort Good Hope are among the 'top four' in the NWT. The "others" consist of oral, stomach, cervical, brain, thyroid and non-Hodgkin's Lymphoma.

Question: Is cancer contagious?

Answer: No, cancer is not contagious. Cancer originates from an individual's own cells and you can't pass it onto someone else. This being said, there are a few contagious causes of cancer such as Human Papilloma Virus (HPV) infection that may lead to cervical cancer, Epstein-Barr virus that can cause a form of lymphoma or H. pylori, a bacteria that infects the lining of the stomach and can also lead to cancer.

Question: How many types of cancers are there?

Answer: There are over 200 types of cancers. Basically, cancer can originate from every kind of cell that makes up our body and it can be found in every part of the body.

Question: Why do some families have more cancer?

Answer: Some cancers have a hereditary (genetic) aspect, meaning that there is something in the genes of certain families that make them more prone to the development of certain cancers. Families also share a similar living environment, eat more of the same foods and may share more similar lifestyles, which can all contribute.

Question: Twenty years ago we were told smoking causes cancer but why do we have cancer now?

Answer: It's important to stress that cancer can take decades to grow. In other words, what we were doing twenty years ago may be contributing to the cancers of today. For example, skin cancer diagnosed in a 50 year-old individual may have started after a bad sunburn when that person was a teenager. That

being said, smoking is still one of the most important risk factors for cancer, not just cancer in the lungs, but in many other parts of the body.

Question: Can radiation in x-rays cause cancer?

Answer: The radiation from x-rays, using modern equipment and techniques, is quite tiny and not considered to be a significant risk factor.

Question: We have asbestos within the walls of our old school. We know that asbestos can cause cancer. Can hanging pictures on the school walls cause cancer from it (asbestos)?

Answer: There is a specific type of lung cancer that is attributable to exposure to asbestos but there is no risk unless the asbestos is disturbed and inhaled. As long as the asbestos is contained within the walls of the school it poses no risk. Small holes from thumb tacks or push pins are not long enough or big enough to penetrate through drywall.

Question: What if someone smokes; what is their risk?

Answer: It is important to note that cancer risks are cumulative; for example, H. pylori infection may double the risk of cancer in the stomach, but if the person also smokes, the risk will be six to eight times greater and regular consumption of alcohol increases the risk even more. Certain vitamins and foods actually protect against cancer, so if you miss them because of poor diet, then your risk of cancer will increase again.

Question: Where can we get the FIT (Fecal Immunochemical Test) Test, the screening kit for colorectal cancer?

Answer: FIT tests are available at the Health Centre. These tests can be taken home and then brought back with the sample to the Health Centre. Because of the high incidence of colorectal cancer here in the NWT, everyone over the age of 50 should participate in this screening program.

Question: What is the cure rate for colorectal cancer?

Answer: If colorectal cancer is detected early the cure rate can be as high as 90%. Screening is really important!

Question: What about light bulbs (CFC's), cell phones, Wi-Fi; can these items cause cancer?

Answer: Research has deemed the risk associated with these items as negligible or so small to not be considered to pose a threat to the health of people.

Question: Do microwave ovens cause cancer?

Answer: Although microwave ovens use radiation to heat food and beverages, as long as the microwave components and protective barriers are not damaged and in good working order there is no risk to your health or increased risk for cancer.

Question: Why does our community have such a high rate of cancer?

Answer: Cancer is a common disease in all populations. For example two in five Canadians will develop cancer through-out their lifespan and one in four Canadians will die from cancer. Another factor is the more old people you have in your community the more cancer you will see because it is rare in young people and cancer is more common over the age of 50. Part of any increase in cancer is a natural increase due to an aging population. However, the overall prevalence of various risk factors also plays an important part.

Question: What is the most common cancer in Fort Good Hope?

Answer: Colorectal cancer is the most common cancer in Fort Good Hope and the Northwest Territories. Medical officials believe that colorectal cancer is the most common cancer because of the loss of traditional foods in the diets of the people. Junk foods won't cause cancer but they don't have the protective factors against cancer that traditional foods do.

Question: What kind of cancer does smoking cause?

Answer: Smoking increases all kinds of cancer. The most common is lung but it also causes cancer of the bladder, breast, liver, etc.

Question: What are the risks of smoke from tanning the hides?

Answer: All smoke is damaging including wood smoke.

Question: Is it the smoke from cigarettes that causes lung cancer?

Answer: Yes, as mentioned all types of smoke cause damage to the cells in the lungs. However, smokers who have a good diet have a lower risk of cancer. As mentioned earlier, having a healthy diet decreases the risk for developing cancer.

Question: Are berries healthy foods and can they protect people from cancer?

Answer: Berries contain very protective ingredients that can repair damaged cells and protect against cancer. They are also known to decrease the risks of heart disease, diabetes and other chronic diseases as well.

Question: What are the biggest causes or risk factors for cancer?

Answer: The number one cause of cancer is smoking; ranking at number two is not eating the right foods.

Question: How about mercury in the fish we eat, can the fish cause cancer?

Answer: Contaminants can come from anywhere around the globe. For instance the biggest source of mercury in fish comes from burning coal (in China and elsewhere). Exposure to high levels of mercury is associated with many health effects (especially neurological), but not specifically with cancer. However, even if fish has some levels of mercury, fish also has other nutrients such as selenium that may protect against the adverse effects of contaminants like mercury. Healthy foods contain many protective factors within them.

Question: Won't contaminated water cause cancer?

Answer: We test our drinking water on a regular basis. While some contaminants show up in the water in parts per billion, just consider that chemicals in cigarettes are in parts per 100. The arsenic in the water isn't considered a risk to health in the water in the area. Cigarette smoking on the other hand is more of a risk to health.

Question: How does the immune system help to protect us from cancer?

Answer: The immune system plays a big part in repairing damage to our cells. Stress, depression and lack of exercise or poor diet all affect the immune system and can impair its ability to repair damage to our cells.

Challenges in the Cancer Pathway - What can the community do about it?

On the afternoon of the second day, in order to identify the challenges and opportunities in the cancer pathway for Fort Good Hope, the participants broke into groups based on animals that could be found in their region. The Prevention group were the Bears, the Early Detection and Screening group were the Bison, the Diagnosis group were the Moose, the Treatment group were the Eagles, and the Survivorship/Palliation - End-of-Life Care group were the Wolves and Beavers. Participants were asked to identify in their groupings the challenges and opportunities in navigating the cancer journey of:

Prevention – Early Detection/Screening – Diagnosis – Treatment – Survivorship/Palliation



Prevention: The chance of developing cancer (and many other chronic diseases) is reduced with a healthy lifestyle. (Source: Cancer Care Ontario *Let's take a stand against...Colorectal Cancer!* Reference Manual)

Screening: Screening is testing for a disease in a person who does not have symptoms of the condition. Screening is used to detect a condition before it becomes serious, and when it is readily treatable. (Source: Cancer Care Ontario *Let's take a stand against...Colorectal Cancer!* Reference Manual)

Diagnosis: Cancer is diagnosed (confirmed) through various methods and tests. Identifying the stage of disease is a critical aspect of cancer diagnosis. Accurate staging helps patients understand their prognosis and is essential in determining the best treatment options. (Source: www.cancercare.on.ca)

Treatment: Once a diagnosis has been made, and cancer has been confirmed, the next part of the cancer journey is the treatment phase. There are three main ways to treat cancer: surgery, cancer drugs (chemotherapy), and radiation. While surgery entails the removal of tumours, the goal of chemotherapy and radiation is to stop or slow the growth of cancer cells. (Source: www.cancercare.on.ca)

Survivorship: The health and life of a cancer survivor.
(Source: CancerCare Manitoba & Saint Elizabeth Cancer Pathways project survey)

Palliation: Palliative care is more than providing comfort at end-of-life care. It includes pain and symptom management, caregiver support, psychological, cultural, emotional and spiritual support, as well as bereavement support for loved ones. (Source: www.cancercare.on.ca)

Prevention (Bears)

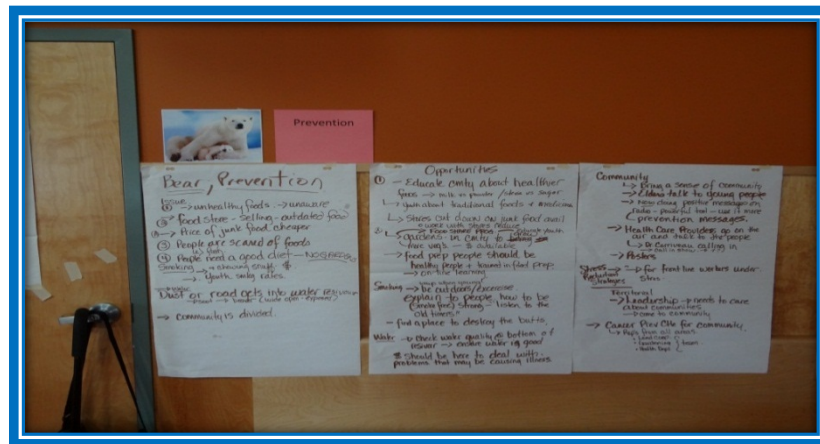
Prevention

The group participants believe that advocacy is a gap. Family members and friends need to be empowered with the necessary education so that they can act as advocates, particularly by encouraging friends and family to go for cancer screening. Education, in addition to cancer prevention and screening, will include self-advocacy with tips such as making a list of questions, their symptoms (including duration), and any medications when they attend their doctor visits. This was viewed as essential in order to get optimal, preventative care, including screening. Advocacy also radiates out to the community level in the ideal pathway, where it is essential that communities are educated on both prevention, and advocating for prevention. Community members who have experienced or are experiencing cancer journeys can also share their stories in an effort to encourage others to take preventative measures.

Funding

Participants explained that there is a lack of overall funding for the community and community programs.

“Money shouldn’t be a problem...but it is. We still need money for studies, research!” (Sharing Session Participant)



Early Detection and Screening (Bison)

Access/Availability

While there are many types of cancers, not all cancers have screening tests and for those that have screening tests, not all are routinely used to screen healthy individuals. The NWT has clinical practice guidelines for screening of cervical, breast and colorectal cancers. There are no clinical practice guidelines for routine screening for prostate cancer in healthy men in the NWT, however screening is offered if symptoms warrant further investigation.

At present three of the four cancer screening tests are available locally in the community:

1. Pap tests for cervical screening
2. FIT screening kits for colorectal cancer

3. PSA screening test (blood test) for prostate cancer

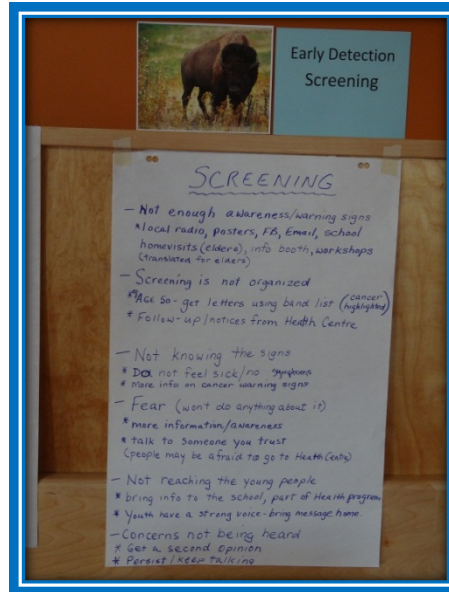
Breast screening (mammograms) is not available locally but is available in Inuvik and Yellowknife.

A gap identified was the lack of knowledge of cancer screening available within the community. Participants expressed that they were unaware the FIT screening kits were available at the health centre.



Participants also expressed they were aware that Human Papillomavirus (HPV) vaccinations were being offered to students in the school but were unaware that the vaccine protects against specific strains of cancer of the cervix.

Health staff members reported that announcements were made every Wednesday morning on the local radio station about the availability of "Health Screening" at the Health Centre. The health providers and participants acknowledged that the word "cancer" should be included in the radio announcements with explanations about what cancer screening is, and types of screening available, along with who should be screened. Participants felt that using the word "cancer" in announcements will increase attendance to the wellness screening clinics.



Diagnosis (Moose)

Diagnosis

Participants explained that community members must travel to Yellowknife, Edmonton or Inuvik for diagnostic services such as CT scans, colonoscopies and mammograms.

Escorts and Medical Travel

Participants reported that there is a need for support services for escorts of cancer patients. The group identified that supports needed were financial, training, and the need for alternate escorts if time away from the community is extended (one-three weeks), which currently isn't supported by Medical Travel.



Treatment (Eagles)

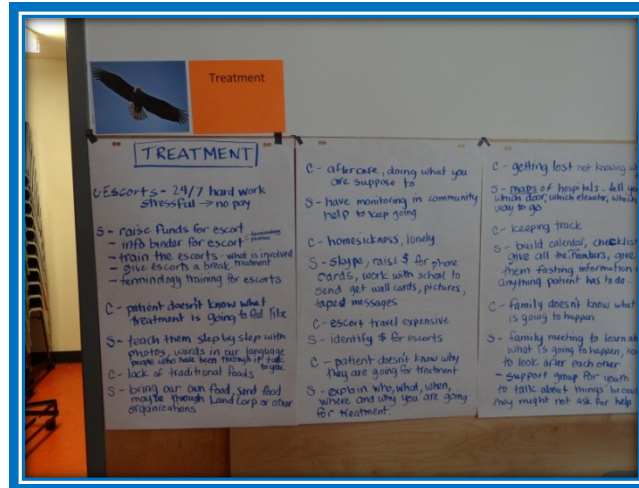
Treatment

For residents of this isolated First Nation community, treatment takes place in Yellowknife, Edmonton or Inuvik.

A cancer patient is supported in accessing treatment by the health centre, and travel is coordinated by Medical Travel. Doctors and other medical staff at the treatment site are responsible for keeping the First Nation community, cancer patient and family well informed.

Jurisdiction

Participants explained that there is confusion on the roles and responsibilities of the territorial government and departments.



Survivorship/Palliation – End-of-Life Care (Wolves and Beavers)

Survivorship/Palliation – End-of-Life Care

Participants explained that survivors remain on their cancer journey even though they are well, for they must continue going to follow-up appointments, and they also need emotional and psychological support.

There is no organized palliative care in the community. Families must step in to provide care, and RNs will administer pain medications. Home and Community Care provides support as well as supplies such as adjustable beds and medical lifts. Both RNs and doctors provide basic training to families on how to care for a palliative family member. A barrier to in-community palliative care is there is not a dedicated worker trained in palliative care.

Supports for Caregivers and Escorts

As participants mentioned in the section on Escorts and Medical Travel in Diagnosis, there is a lack of support, both emotional and financial, for escorts accompanying patients to cities. Lack of awareness of their surroundings in unfamiliar cities leads to fear and anxiety amongst both patients and escorts.

Participants identified the need for caregiver supports and education on self-care. Caregiver burn-out is common especially for those caring for others requiring long-term care or palliative.

Communication and Coordination of Care

Participants identified numerous gaps and barriers in the coordination of cancer care between the community Home and Community Care Program and the Cancer Treatment Centres. This issue was best illustrated by the story of one participant, a cancer survivor, who was discharged after surgery and told to go home by the treatment centre staff in Edmonton. The patient went home to his home community without the knowledge of the Home and Community Care staff within the community. The treatment centre discharge plan was to send the client to accommodations in Edmonton (Larga) until he was well enough to be discharged home to the community. This facility provides in-house supports and services for clients not well enough to return to their home communities. However when told he could go 'home' the community member understood this to mean Fort Good Hope and not Larga. It was a number of weeks before the miscommunication was discovered and Home and Community Care services were provided within the community. The participant explained during the initial sharing circle "I had to take care of myself, I had nobody, and I had this bag (Ostomy) and this other tube in my bladder." (Sharing Session Participant)

Transportation

The lack of Medical Travel funding for transportation for escorts and alternates, and policies as mentioned previously, is an ongoing challenge.

Resources

There is a lack of cancer resources for health care workers in Fort Good Hope, and participants discussed the fact that this is a barrier affecting all of the challenges mentioned in this section. Participants explained that there is a lack of culturally appropriate resources around the cancer journey.

Mental Health Services

Currently, there are mental health services or supports within the community of Fort Good Hope in dealing with the emotional and psychological effects of cancer. There is a Mental Health and Addictions Counselor who offers services within the community. In addition, a visiting psychiatrist offers services within the community every second month for a day.

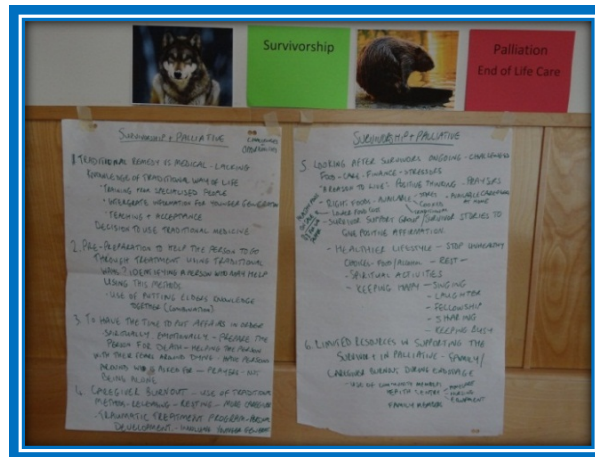
Aftercare for Survivors

At present in Fort Good Hope there are no support or aftercare programs for cancer survivors, and participants agreed this is a significant gap in the current cancer pathway.

Education/Awareness and Training


In reference to the misconceptions about cancer that were outlined previously in the session, the participants explained that there is a lack of education in Fort Good Hope for frontline staff, especially Home and Community Care providers, around cancer. As well, participants expressed that within the community there is a great deal of fear around cancer, and there is not enough education and advocacy work being done to address this. Throughout the activities participants expressed the need to know:

- What is cancer?
- How do we prevent it?
- What the community can do?




As discussed, sharing session participants were asked to discuss challenges and opportunities/potential solutions to address these challenges. Participants tackled this task with enthusiasm and were able to identify multiple practical and realistic solutions, many that the community itself could undertake. These challenges and solutions are presented below.


In order to support community efforts to implement or advocate for these solutions the challenges and solutions are presented in **Appendix B**, including sample activities and those activities currently underway within a work-plan format. The work-plan template has been drafted to be used by the community for planning purposes.


Cancer Pathway	Challenge	Opportunity/Solution
Prevention 	Food <ul style="list-style-type: none"> • People unaware of what is and isn't healthy • Food store selling outdated food • Price of junk food is cheaper than healthy food • People are scared of foods from the land and fish • There is no interest in gardens; years ago Fort Good Hope had big gardens that grew turnip, potatoes, and carrots. Community garden now – only three people showed up to plant and be a part of it. 	Educate community about healthier foods: <ul style="list-style-type: none"> • Milk versus powder and Stevia versus sugar • Educate youth about traditional foods and medicines • Work with stores to cut down on junk food available • Start a food share program • Get people motivated to participate in the


		<p>community garden</p> <ul style="list-style-type: none"> • Educate youth about gardening and what was done in the past • There is money available to communities for developing gardens • Educate people who are preparing food for the community about food preparation
	<p>Water</p> <ul style="list-style-type: none"> • Need to know if something is wrong with it • Dust from the road gets into the reservoir because it is wide open and exposed, and the dust settles into it. One time people found a dead beaver in it. 	<ul style="list-style-type: none"> • Have the water at the bottom of the reservoir checked to ensure water is good and let the community know • Ensure the money is available to the community to deal with these problems
	<p>Community</p> <ul style="list-style-type: none"> • Community does not come together • Don't talk about these things • Need to be more active and get involved 	<ul style="list-style-type: none"> • Bring a sense of community back through having Elders talk to young people • Just starting to do more positive messaging on the radio – radio is a powerful tool - we need to use it more for prevention messages. Tell people that cancer screening is available to them. • Health care providers go on the air and talk to the people; they will be less shy if they can phone in and ask questions – ask Dr. Corriveau to do this. • Create posters – they are a good tool


		<ul style="list-style-type: none"> • Help to create stress reduction strategies for frontline workers • Territorial Leadership needs to care about communities and come out to the communities • Create a cancer prevention committee for the community, with representatives from all areas in the community: <ul style="list-style-type: none"> ○ Land Corporation ○ Gardening ○ Health department ○ Cancer survivors
	<p>Smoking</p> <ul style="list-style-type: none"> • People spend money on cigarettes and snuff instead of good food • Youth smoking rates are high • People don't know how bad it is 	<ul style="list-style-type: none"> • Educate youth about what smoking does to you long term • Educate community about smoke getting into your clothes and how it stays on and in your body • Help community to see that smoking should not be an accepted thing
<p>Early Detection/ Screening</p> 	<p>Cancer Awareness</p> <ul style="list-style-type: none"> • Not enough awareness of screening, early detection • Not knowing the warning signs of cancer • Not knowing you may not have warning signs, that you might not feel sick 	<ul style="list-style-type: none"> • Use local radio-everyone listens to radio • Put our own posters around the community • Use Facebook and email • Go to the school and teach the kids who can go home and tell their parents and grandparents. Do home visits to all the Elders, have information booth at community events. • Do workshops

		<ul style="list-style-type: none"> Make sure the information is translated for Elders.
	<p>Screening</p> <ul style="list-style-type: none"> Screening is not organized 	<ul style="list-style-type: none"> Work with band office, send letters to every person 50 plus on the band list to tell them about FIT test screening for colorectal screening. Make sure you highlight that this is about cancer. Do follow up letters from health centre
	<p>Fear</p> <ul style="list-style-type: none"> Are afraid so won't do anything about warning signs 	<ul style="list-style-type: none"> Need more information/awareness about increased survival rates from screening and early detection. The more survivors the community has the less fear there will be; cancer will be seen as something that can be beaten, not a death sentence. People may mistrust the health care system due to residential school history. Do an information campaign encouraging people that if they have concerns, go to the health centre or tell someone they trust.
	<p>Youth</p> <ul style="list-style-type: none"> Not reaching the young people 	<ul style="list-style-type: none"> Need to bring the information to the school, make information on cancer part of the health curriculum. Youth have a strong voice and will bring the

		messages home.
	Being Heard <ul style="list-style-type: none"> Concerns are not always heard. May go to doctor/nurse concerned about warning signs and told it is nothing to worry about 	<ul style="list-style-type: none"> Get a second opinion, persist and keep talking. Find someone who can help advocate for you.
Diagnosis 	Support	<ul style="list-style-type: none"> Develop support group(s) Contact Liaison Escort alternate Escort assistants
	Qualified interpreters	<ul style="list-style-type: none"> Teach using local radio and within classrooms (school) Use recording devices for teaching Listed qualified interpreters (current contact lists available)
	Caregiver Training	<ul style="list-style-type: none"> RN to provide training
	Jurisdiction	<ul style="list-style-type: none"> Identify department responsibilities
	Change Life Style	<ul style="list-style-type: none"> Healthy foods and lifestyle
	Mental Health Care	<ul style="list-style-type: none"> Traditional camps/regional (Sahtu)
	Continuity	<ul style="list-style-type: none"> Partner with other groups or regions
	Transportation	<ul style="list-style-type: none"> Be comfortable during travel
	Carry-on Medications (e.g. liquid morphine, oxygen)	<ul style="list-style-type: none"> Provide exceptions to special patients

	Accommodation	<ul style="list-style-type: none"> Identify needs and support (advocates)
	Escort Supports <ul style="list-style-type: none"> 24/7, hard work, stressful, no pay 	<ul style="list-style-type: none"> Raise funds for escort Info binder for escort (terminology, photos) Train the escorts - what is involved (treatment) Give escorts a break Terminology training for escorts
Treatment 	Treatment Education <ul style="list-style-type: none"> Patient doesn't know how treatment is going to feel like 	<ul style="list-style-type: none"> Teach them step by step with photos, words in our language, people who have been through it talk to you
	Traditional Foods <ul style="list-style-type: none"> Lack of traditional foods 	<ul style="list-style-type: none"> Bring our own food Send food, maybe through Land Corporation or other organizations
	After Care <ul style="list-style-type: none"> Doing what you are supposed to 	<ul style="list-style-type: none"> Have monitoring in community, help to keep going
	Homesickness and loneliness	<ul style="list-style-type: none"> Skype Raise money for phone cards Work with school to send get well cards Pictures Taped message
	Escort <ul style="list-style-type: none"> Travel expensive 	<ul style="list-style-type: none"> Identify money for escorts
	Treatment Education <ul style="list-style-type: none"> Patient doesn't know why they are 	<ul style="list-style-type: none"> Explain who, what, when, where and why you are going for

	going for treatment	treatment
	Navigation <ul style="list-style-type: none"> Getting lost, not knowing where to go 	<ul style="list-style-type: none"> Maps of hospitals, tell you which door, which elevator, which way to go
	Keeping track	<ul style="list-style-type: none"> Build calendar Checklists Give all the phone numbers Give them fasting information or anything patient has to do...
	Family Education and Supports <ul style="list-style-type: none"> Family doesn't know what is going to happen 	<ul style="list-style-type: none"> Family meeting to learn about what is going to happen, how to look after each other Support group for youth to talk about things because they might not ask for help
	Traditional Remedy versus Medical <ul style="list-style-type: none"> The medical model is lacking as it focuses on the body (physical) and does not include the other three dimensions (mental, emotional and spiritual) 	Knowledge (Education) of traditional way of life: <ul style="list-style-type: none"> Training from specialized people Integrate information for younger generation Teaching and acceptance Decision to use traditional medicine
Survivorship 	Treatment <ul style="list-style-type: none"> Pre-preparation to help the person to go through treatment, which will include traditional ways 	<ul style="list-style-type: none"> Identifying a person who may help using these methods Bringing Elders' together to share their knowledge
Palliation	Palliation Supports	<ul style="list-style-type: none"> Spiritually, emotionally-prepare the person for death

	<ul style="list-style-type: none"> • To have the time to put affairs in order • The need to respect the wishes of the individual, i.e. there are times the person may want to be alone and there are times they may want company • Request for information on how to speak to someone who is ill or dying – fears about ‘saying the wrong thing’ 	<ul style="list-style-type: none"> - helping the person with their fears around dying. • Have people around who are asked for prayers - not being alone
	<p>Caregiver burnout</p> <ul style="list-style-type: none"> • Must take care of yourself before you can help others 	<ul style="list-style-type: none"> • Use of traditional methods-releasing-resting-more caregivers • Traumatic treatment program - personal development - involving younger generation
	<p>Survivorship Supports</p> <ul style="list-style-type: none"> • Looking after survivors 	<ul style="list-style-type: none"> • Needs to be ongoing • Food-care- finance- stressors • “A reason to live”- positive thinking- prayers • Right foods - available <ul style="list-style-type: none"> ○ Stores ○ Cooked ○ Traditional ○ Available caregivers at home ○ Lower food cost- healthy foods on sale (e.g. \$8.00 for one green pepper) • Survivor support group/survivor stories to give positive affirmation • Healthier lifestyle - stop unhealthy choices: food/alcohol- rest • Spiritual activities

		<ul style="list-style-type: none"> • Keeping happy - singing, laughter, fellowship, sharing, keeping busy
	Resources- Survivorship and Palliation <ul style="list-style-type: none"> • Limited resources in supporting the survivor and in palliative 	<ul style="list-style-type: none"> • Family/caregiver burn-out during end-stage • Use of community members • Health Centre - home care, nursing, equipment • Family members

Opportunities for Improving the Cancer Journey for Fort Good Hope



Throughout the sharing session, many opportunities were identified and they are presented according to the major themes as follows:

Coordinated Chronic Disease Approach

For the community of Fort Good Hope cancer is a chronic disease. During the group discussions participants identified other chronic diseases in the community such as diabetes and heart disease that share some of the same risk factors as cancer. Preventative measures such as physical activity, not smoking and proper nutrition, for example, are applicable to numerous chronic diseases. With this in mind there are opportunities for a coordinated chronic disease approach within the community.

Culture

According to participants, a support in navigating the cancer pathway would include culturally appropriate resources specific to the community of Fort Good Hope and regionally similar communities. At present both community and health care provider participants were unaware of resources developed specifically for the territories which support the cultural and regional realities.

Empowerment and Advocacy

Participants shared that there are many opportunities for empowerment along the cancer pathway, particularly in the areas of self-advocacy and community advocacy. Through education about cancer, self-care, and the creation of hope amongst cancer patients and their families and friends, the community will be more empowered in taking control over their cancer journeys and in preventing cancer. Participants feel there are many opportunities for advocacy along the cancer pathway, particularly in the context of education.

Transportation and Improvement in Medical Travel

Due to the fact that members of their community often travel outside of their home community (south) for treatment, participants spoke often about systemic problems in the Medical Travel policies. There was concern from participants around the lack of supports from Medical Travel, particularly in that Medical Travel does not cover travel costs for escorts for all cancer clients when traveling for treatment. Participants recommended that Medical Travel, the territorial government and representatives from the community meet together with the goal of making policies more sensitive to First Nation community needs and reducing barriers/challenges for clients and their families and escorts.



Transportation policies and accommodations were also challenges for those travelling for cancer treatment. Participants explained that community members travelling by air have specific needs of a private area (accommodations) within the airports where ill passengers can lay down and rest. Community members with cancer are often ill, suffering the effects of the disease and struggling with side effects to treatment (nausea, fatigue, dizziness, etc.). It is common that there are hours of delays between flights. Participants also expressed that exceptions to the Air Transportation policies prohibiting the carry-on of liquid medications (e.g. liquid morphine) and oxygen are needed.

Screening Promotion

Participants recommend much greater screening promotion, especially to generate awareness about breast and colorectal cancer.

Screening promotion is tied to education for participants, who feel it is important to begin education around cancer awareness from an early age and include it in the health curriculum within the school.

Support Group for Survivors

There are no current aftercare programs or supports for cancer survivors in Fort Good Hope and participants recommend a dedicated group for cancer survivors to provide ongoing support to one another.

Palliative Care in Communities

Participants recommend improvements to in-community palliative care, particularly so that palliative clients can die with dignity in their own home and community. They also recognized the need for hands-on training for palliative care providers, health care providers, family members and caregivers.

Participants also recommend grief counseling for palliative patients and their families and to include activities targeting the youth in this counseling, as participants felt they don't ask for help or don't know how to deal with grief.

Holistic Health Care

Participants believe that approaches to health care should be holistic, incorporating the physical, mental, emotional and spiritual needs of patients in culturally appropriate and respectful manners. This was a theme that was interwoven throughout the session activities. Holistic health care should also involve an integrated and coordinated chronic disease prevention model of care as discussed earlier.

The Tree of Hope

Hope stands firm with participants in that they have taken the first step of many to come in improving the cancer journey and decreasing the incidence of cancer in the community of Fort Good Hope. At the end of the sharing session, participants participated in the building of the *"Tree of Hope"*.



The hopes (leaves) of the participants are as follows:

- Love, Care, Support
- Give love to everyone
- Laugh loud, sing proud, and be happy
- Spiritual is key
- Government needs to hear us
- Never give up
- Love yourself
- Better our health care power
- I still love you
- Camping on the land for resting and sharing
- Stay positive in your own way happy
- Sahtu Cancer Roundup
- We stand with you
- Dances and talent show healing!! Love one another
- Keep on drumming sing the songs with your heart
- Never give up look for the sunshine each day
- Beat cancer-all will survive cancer
- Help one another give hope
- Hope for a cancer free community
- There is strength in working together
- Laughing and be happy all the time
- I love you
- Happiness
- Hope-give
- Share and love one another
- Laugh and sing

- Singing and dancing
- We are the Kasho Got'ine we will be here always!
- The community of Colville Lake is thankful for this workshop on cancer
- Traditional food. Drums
- We are thankful for the medical staff
- I draw strength from my Grandmother. She is a powerful role model
- Live, Love, Laugh
- Respect, Love, Joy, Hope, Sharing
- **Let the tree grow, not cancer!**
- Be a survivor, faith, positive attitude, laughter
- Struggle with cancer may end soon
- People will get help to heal and talk and stay healthy
- Sharing

Conclusion



This sharing session represents an important first step in making a difference around cancer in the community of Fort Good Hope. Community participants, community Leadership and health providers had a shared desire for knowledge and a willingness to take community action to improve the current cancer journey for the people of Fort Good Hope. The participants identified the challenges across the cancer pathway and developed initial opportunities/solutions to address these challenges, many of which the community could implement right away.



This strong desire to take action is demonstrated by the fact that before this report was written, action toward addressing challenges was already underway. The day after the sharing session, a meeting was held between health centre staff members, the Saint Elizabeth sharing session facilitators and two cancer survivors (participants in the sharing session). The results of the meeting held at the Cassien Edgi Health Centre are as follows:

1. Cancer Support Group: Plans and stated commitment from the cancer survivors and the health staff to start the support group. Supports will be provided by the Home and Community Care Program, caregivers and the Mental Health and Addictions Counselor.
2. Cancer Treatment Fact Sheets: The need for culturally appropriate information on cancer treatment was identified during the sharing session as a gap within the current system. The plan to meet this need is that the sharing session facilitators will initiate a partnership between Fort Good Hope and CancerCare Manitoba. The partnership will include the provision of the Cancer Treatment Fact Sheets (developed in 2011) by CancerCare Manitoba and the translation of the fact sheets into North Slavey by Fort Good Hope for the use by the community. The CancerCare Manitoba Cancer Treatment Fact Sheets are currently available in several First Nation Languages (Cree, Ojibway and Oji-Cree) and can be found on the CancerCare Manitoba website at:
http://www.cancercare.mb.ca/home/patients_and_family/cancer_treatment_information/
3. Cancer Basics Information Booklet: This item was also an identified gap during the sharing session. The development of a booklet outlining the cancer basics has already begun. The booklet will be developed by the Saint Elizabeth First Nations, Inuit and Métis Program, Sahtu Health and Social Services Authority, and the Government of Northwest Territories. The purpose

of the booklet is to help educate the community about cancer basics, and to share with the broader community information on cancer in Fort Good Hope, including screening available. To support uptake of the information by the community the booklet will incorporate local images. The booklet is intended to be readily available as a take-away item provided by the health centre and the content is to be used for public service announcements on the local radio station. The content can also be translated by the community from English to North Slavey. The information booklet will cover the following topics:

- What is cancer?
- What are risk factors?
- How can cancer be prevented?
- Screening for cancer
- Warning signs for cancer
- Cancer fast facts
- Where to go for more information

Several cancer resources were discussed during the sharing session by various participants and presenters. These resources are listed in **Appendix C**.

The final reflections sharing circle was very positive; participants expressed their ongoing commitment to working together toward solutions for the challenges identified in the cancer pathway. Here are three examples of what the participants shared:

“As long as we stick together and be strong we can beat this (cancer)!” (Sharing Session Participant)

“When I first came to this workshop...I didn’t know what to expect. My work doesn’t end at 4 o’clock, cancer is plaguing our community...Lets not stop here!” (Sharing Session Participant)

“Before the group came, we were all at a standstill looking over a cliff wondering who is going to fall next. Now we have hope, we have taken a step back from the cliff...” (Sharing Session Participant)




Appendices


Appendix A: Fort Good Hope Cancer Sharing Session Agenda


Day 1: June 18, 2012	
Timeframe	Activity
5:00 – 5:45 pm	Meet and Greet
	Name Tags Stations Children's Activity
5:45 – 6:00 pm	Elder Opening Remarks & Prayer
6:00 – 6:15 pm	Welcome
6:15 – 6:30 pm	Facilitator Introduction and Purpose of Gathering
6:30 – 7:00 pm	Introductions (Sharing Circle)
7:00 – 7:30 pm	Expectations (Group Activity)
7:30 – 7:45 pm	Break
7:45 – 8:00 pm	Energizer 1
8:00 – 8:50 pm	Celebrating the Community
8:50 – 10:00 pm	Wrap up and Reflections Day 1 (Sharing Circle)


Day 2: June 19, 2012	
Timeframe	Activity
8:30 – 9:30 am	Breakfast
9:30 – 9:40 am	Welcome Back
9:40 – 10:00 am	Community Perceptions of Cancer (Group Activity)
10:00 – 10:15 am	What is Cancer?
10:15 – 10:30 am	Break
10:30 am – 12:00 pm	GNWT Health Official – Dr. Corriveau Presentation What is Cancer? Cancer Prevention and Awareness Cancer Incidence in the NWT, Sahtu and Fort Good Hope
12:00 – 12:45 pm	Lunch
12:45 – 1:00 pm	Energizer 2
1:00 – 2:45 pm	Community Challenges and Opportunities Around Cancer
2:45 – 3:00 pm	Break
3:00 – 3:30 pm	Wrap up Activity Community Tree of Hope
3:30 – 5:00 pm	Closing Remarks (Sharing Circle)

Appendix B: Fort Good Hope Cancer Control Work-plan Template



Cancer Pathway	Challenge	Activities	Person Responsible & Resources Required	Timeline/ Target Dates	Outcome	Progress
Prevention 	Community Cancer Awareness <ul style="list-style-type: none"> Not enough awareness of screening, early detection Not knowing the warning signs of cancer Not knowing you may not have warning signs, that you might not feel sick 	Development of a cancer basics information booklet. The purpose of the booklet is to help educate the community about cancer basics, and to share with the broader community information on cancer in Fort Good Hope, including screening available. The information booklet will cover the following topics: <ul style="list-style-type: none"> What is cancer? What are risk factors? How can cancer be prevented? Screening for cancer Warning signs for cancer Cancer fast facts Where to go for more information 	Development: Saint Elizabeth First Nations, Inuit and Métis Program Sahtu Health and Social Services Authority Government of Northwest Territories. Translation: Community Translators (North Slavey)	August 2012	Availability of a Cancer Basics Information Booklet to be used for education purposes including public service announcements on the local radio station	

Cancer Pathway	Challenge	Activities	Person Responsible & Resources Required	Timeline/ Target Dates	Outcome	Progress
Early Detection/ Screening 	Organized and Coordinated Screening Program <ul style="list-style-type: none"> Screening is not organized 	Screening Letters for Colorectal Cancer <ul style="list-style-type: none"> Work with band office to identify all on the band list who are 50 plus Send letters to every person 50 plus on the band list to tell them about FIT test screening for colorectal screening. Make sure you highlight that this is about cancer. Follow-up letters for non-responders 	Band Clerk-band list Health Staff Member-develop & distribute letters Health Staff Member	To be determined		
	Youth Education <ul style="list-style-type: none"> Not reaching the young people 	Incorporate cancer awareness and cancer prevention into the School Health Curriculum <ul style="list-style-type: none"> Youth have a strong voice and will bring the messages home 				

Cancer Pathway	Challenge	Activities	Person Responsible & Resources Required	Timeline/ Target Dates	Outcome	Progress
Diagnosis 	Support	Start a Cancer Support Group	Cancer Survivors Health Centre Staff Supports to the group from: Mental Health & Addictions Counselor Home and Community	Summer 2012	Cancer Support Group in Action with meetings as decided by the group	

Cancer Pathway	Challenge	Activities	Person Responsible & Resources Required	Timeline/ Target Dates	Outcome	Progress
			Care Staff Caregivers			
	Escort Supports <ul style="list-style-type: none"> Escorts, 24/7 hard work, stressful, no pay 	Fundraising Activities: To raise funds for escorts Develop an information binder for escorts (terminology, photos) Escort Training- what is involved (treatment) Terminology training for escorts				
Treatment 	Treatment Education <ul style="list-style-type: none"> Patient doesn't know how treatment is going to feel like 	Cancer Treatment Fact Sheets Sharing Session facilitators will initiate a partnership between Fort Good Hope and CancerCare Manitoba.	Sharing Session Facilitators (SE FNIMP)	Summer 2012	Availability of culturally appropriate Cancer Treatment Fact Sheets in	

Cancer Pathway	Challenge	Activities	Person Responsible & Resources Required	Timeline/ Target Dates	Outcome	Progress
		<p>Provision of the Cancer Treatment Fact Sheets (developed in 2011) by CancerCare Manitoba. The CancerCare Manitoba Cancer Treatment Fact Sheets are currently available in several First Nation Languages (Cree, Ojibway and Oji-Cree) and can be found on the CancerCare Manitoba website at: http://www.cancercare.mb.ca/home/patients_and_family/cancer_treatment_information/</p> <p>Translation of the fact sheets into North Slavey for use by the community.</p>	<p>CancerCare Manitoba-current Cancer Treatment Fact sheets</p> <p>Fort Good Hope/GNWT Translation Services</p>	Fall 2012	North Slavey.	

Cancer Pathway	Challenge	Activities	Person Responsible & Resources Required	Timeline/ Target Dates	Outcome	Progress
Survivorship 	Caregiver Support <ul style="list-style-type: none"> Burn-out prevention 	Develop Caregiver Information on How to Prevent Burn-out <ul style="list-style-type: none"> Education on the use of traditional methods-releasing-resting 				
Palliation 						

Appendix C: Fort Good Hope Identified Cancer Resources

The purpose of this listing is to highlight cancer resources that may be helpful to the community and/or were discussed during the sharing session by the facilitators and presenters. The resources are not limited to the Northwest Territories and contain resources from other provinces/territories. For example, the Cancer Bridges resource is listed in order to assist in the communities planning of the Fort Good Hope Cancer Support Group.

***Please note this list is not meant to be an exhaustive list of cancer resources.**

- CancerView Canada
http://www.cancerview.ca/cv/portal/Home/FirstNationsInuitAndMetis?_afrLoop=1042816307503000&_afrWindowMode=0&_adf.ctrl-state=1c45c9ux7c_95
On CancerView Canada, a site that connects Canadians to cancer services, information and resources, there is a Community of Information page on resources on cancer control for First Nations, Inuit and Métis peoples. On this page, there are videos where people share their personal cancer journeys, as well as a knowledge circle with links to publications and research on cancer prevention, testing, treatment, and living with cancer. This section of CancerView is still in development, in cooperation with partner organizations such as the Canadian Partnership Against Cancer and Saint Elizabeth.
- @YourSide Colleague
www.atyourside.ca
One of the key initiatives of the Saint Elizabeth First Nations, Inuit and Métis Program is @YourSide Colleague, a secure web-based learning and knowledge sharing program that provides more than 10 internet based health related courses (includes the Cancer Care course) to First Nation communities. All of the First Nations courses are developed with community based health care providers from participating First Nation communities and offered at no cost to the communities.
- Alberta/NWT Division of Canadian Cancer Society
http://www.cancer.ca/Alberta-NWT/Support%20Services.aspx?sc_lang=en
In its provincial and territorial regions, the Canadian Cancer Society lists the Northwest Territories together with Alberta. The Canadian Cancer Society is a community organization that supports cancer research, provides information on all cancer types, organizes community programs, and leads initiatives in cancer prevention. (Canadian Cancer Society, 2011)
- Alberta Health Services

Alberta Cancer Information

<http://www.albertahealthservices.ca/Cancer.asp>

Northern Health Services Network

<http://www.albertahealthservices.ca/services.asp?pid=service&rid=4081>

Alberta Health Services Northern Health Services Network (NHSN) helps patients and their families from the Northwest Territories, Nunavut, and the Yukon, who are in Edmonton for specialized medical care at all Alberta Health Services sites.

The NHSN focuses on co-ordination of care, discharge planning, and follow-up services for approximately 6,000 northern patients annually. The NHSN may be able to assist patients and their families from the North meet their language, cultural, and spiritual needs.

Cross Cancer Institute

<http://www.albertahealthservices.ca/services.asp?pid=facility&rid=6122>

The Cross Cancer Institute in Edmonton is the comprehensive cancer centre for northern Alberta and a lead centre for the province-wide prevention, research and treatment program. The Cross Cancer Institute provides advanced medical and supportive cancer care, patient and professional education, and conducts research through the Alberta Cancer Research Institute. For more information on programs and services refer to their website.

- NWT Breast Health/Breast Cancer Action Group

<http://www.breasthealthnwt.ca/>

The goal of the website is to provide easy access to breast health and breast cancer information and resources for people in the Northwest Territories (NWT), Canada. The website contains information on events, issues, resources, services and news related to breast health and breast cancer in the NWT, and new links to other sources of information.

- CancerCare Manitoba

<http://www.cancercare.mb.ca/home/>

Cancer treatment information is available to view and hear (audio) in the following First Nation languages: Cree, Ojibwe, and Oji-cree, and can be accessed at:

http://www.cancercare.mb.ca/home/patients_and_family/cancer_treatment_information/

The information helps answer the following questions:

- Do you want to better understand your or your family member's cancer treatment?
- Are you not sure how to deal with the side effects of treatment?
- Do you need help talking with the doctors and nurses about your care, treatment and side effects?

- Cancer Bridges Survivorship Network

<http://www.cancerbridges.ca/2011/10/survivor-network/>

The Alberta CancerBRIDGES (Building Research Innovation into the Development and Growth of Excellence in Survivorship Care) team is a large provincial collection of people with special interest in researching and delivering evidence-based survivorship care. The team members include researchers, physicians, oncologists and survivors located mostly in Alberta. For more information on the members of the team, please see the 'Who We Are' section of the website.

- Elders' traditional knowledge and medicines – this is a huge knowledge base, and resources, to the benefit of each community
- Sahtu Health and Social Services Authority (SHSSA)
- Department of Health and Social Services, Government of the Northwest Territories (GNWT)
- SHSSA and GNWT Videoconferencing/Telehealth