Detailing the Evolution of Palliative Care in Fort William First Nation: Creating a Timeline

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**Historical Development of Palliative Care**

Prior to the development of Dilico’s home and Community Care program in Fort William First Nation, End-of-Life care was provided through family members, community health nurse, family physicians and Hospice. Funding for such programs is provided by Fort William First Nation and Health Canada. Family members often provided whatever was needed in the area of caring for their family member. This included home making services, personal care, food preparation, medical appointments, and assisting with medications. Family also worked together to provide around the clock in home care as needed. Services that were provided in a formal manner included the provision of limited home making services, food preparation services and some personal care services. When a family member’s illness was to the point when the family could no longer provide the necessary care, the family member was taken to hospital and admitted to the hospice unit. This provided all the necessary care required, with around the clock nursing care available.

Palliative Care in Fort William First Nation is provided by the Health Centre team, which consists of the Community Health Representative, Community Health Nurse, Health Centre Manager, and Dilico Home and Community Care Program. This Team has assisted in bringing Palliative Care to the forefront of this First Nation by becoming involved in the End-of-Life Care Program with Lakehead University. This undertaking is bringing awareness to the members of Fort William First Nation as well as to the leaders and service providers. Learning what is involved in and what Palliative Care consists of, and what is available to members who require the services is creating a starting point to develop services that are required in our First Nation.

The Home and Community Care program came to exist due to the fact that there were no existing services, people wanted better services, and there was an interest in quality end of life care services. The driving force behind this development was the 1985 needs assessment. This was the last time that a needs assessment was complete as far as we are aware. This program was initiated by Dilico and Social Services, the need for the services covered under this were apparent and these two different areas worked to begin to address the needs. The services that were initially provided included home care (limited), referrals to services in the city and home visits.

In 1995 local community and outside agencies began to partner with the First Nation. Palliative care in Fort William First Nation community began with the Welfare (social services) department and then in 1995 Dilico became a part of providing some of the services required in the community. Since then Fort William First Nation has been approached by the University and are now working together towards a palliative care model that will be adaptable to all First Nations.

**The Current Status of Palliative Care in Fort William First Nation**

Currently there are some palliative care services in Fort William First Nation. The agencies that partner with Fort William First Nation to provide these services to its members include Dilico Home and...
Community Care (home care services include light housekeeping, personal care and meal preparation), Hospice Care Units provide the critical care to community members, Shoppers Drug Mart/Shoppers Home Health Care (delivery and provision of medications and supplies).

Essential services that members of Fort William First Nation receive include some financial assistance, family support, and funeral luncheons at no cost to the family. Eligibility requirements include diagnosis of a long term illness and being a registered member of Fort William First Nation. Services are accessed through the health center; referrals can be made by family members, agencies, or self-referrals. Support Services include transportation to appointments, financial assistance for items that are required for care such as medications and supplies. Services are targeted for members who have long term/terminal illness and their families, as well as community members.

Funding is provided under the umbrella of Dilico, funding flows through the agency to the First Nations. Some of the service overlaps include home care through Dilico as well as the First Nation Social Service Department. Palliative Care resources that are currently available include the agencies that assist with the provision of services, the front line staff, and Non-Insured Health Benefits. The future of palliative care in Fort William First Nation would include additional personnel, an elders home, equipment costs, additional funding for items that are not covered under the NIHB program. Working towards a palliative care program in the community.

Fort William First Nation was contacted by the CERAH offices at Lakehead University to take part in the research project. The advancement of palliative care in our community has begun with the staff at Fort William First Nation, the community advisory committee, community facilitator, community members and chief and council.

Fort William First Nation has established a community advisory committee that consists of the health centre manager, the CHR, Dilico staff member, community members (Sherry Pelletier and Jean Pervais. Involvement in the project will assist our community to advance and improve end of life care.

History has shown that support to both Family members and the patient has improved end of life. Being able to be close to family members, having the necessary equipment, education for care givers and family members on illness and caring for the individual adds to the quality of a person at the end of their life or during their sickness.

Community members that have passed on and their families have struggled (financially, with committing to care and emotionally). Our goal is to alleviate some of these additional struggles. We want to make sure that that Members of Fort William First Nation who are suffering and dying from illness have the choice to die in the manner that provides them with dignity either at home or in hospice.

Awareness of palliative care in the community varies, some people see it as care for people who are dying, and old, some see it as care of people who are sick of any age. Education on Palliative care is in
the beginning stages, providing a source for members to access information on palliative care is the beginning. The health center and Dilico are agencies that can provide this source. Staff and service providers are becoming more aware of palliative care through training and involvement in the project.

The current palliative care program has been outlined in this report. Limited services are available to community members. These services do not cover 24 hour care to those in need, nor does it cover all financial obligations for medications or supplies that may be required.

Documentation on services comes in the form of case notes that are held in the member's files at the Health Centre or by the service provider. Documenting these services and the need for more services and funding may provide a starting point for obtaining what is needed.

Fort William First Nation currently partners with Dilico, this partnership assists with services that are provided to community members. Decision making is based on the community member as well as the service provider. The partnership may include an agreement between the band, Dilico and the agencies that are providing service.

Relationships were developed based on services needed and the availability of these services. Agreements between the agencies played a large role in development. Funding for services that are available was applied for through Dilico for the communities under that umbrella, this created a working relationship.

Through this partnership Fort William can access the following services:

- Access to the Dilico team (community health nurses, diabetes educator, care manager, traditional healers, Physicians, Nurse/practitioners, Personal Support Workers, Social Worker and Infant/Child Development Workers
- Community health services provide many opportunities for individuals, families, and communities to reinforce and learn positive health attitudes and behaviours. Focused prevention strategies educate and empower clients to adopt healthy lifestyles.
- Home and Community Care Program which is an in-home and community-based services support the efforts of individuals to care for themselves with the assistance of family, friends, and community. Care management ensures that services meet the needs of the client.
- Family Health Team which provides some primary health care through an interdisciplinary team of physicians, Nurse Practitioners, Nurses, a Social Worker, a Traditional Healer, and Diabetes Educator.
The Future of Palliative Care

Fort William First Nations goals for the future of palliative care include having a model of care that will be adaptable to first nations communities, training for those that require it either to provide care to family members or for Front Line Workers, working on obtaining a facility for our elders, educating our people on what palliative care is and where to obtain the information and services that may be required. In five to ten years we would like to see some of our goals being met, being able to provide the choice to our first nation members on whether they want to leave the community for end of life care or stay in their home, and have the resources available to provide the most dignified end of life we can.

Methodology

The information used to create the historical timeline was supplied by interviews with several key informants and through documents and websites. Key informants were interviewed on several occasions to provide insight into the history and current status of Palliative/End-of-Life care in Fort William First Nation. In order to assist the Community Facilitator in ensuring key questions were asked, a Historical timeline interview guide tool was created by the research team and implemented in community interviews. Key informants supplied valuable information regarding the history of health care services in Fort William First Nation; evolution and current status of Dilico Home and Community Care; palliative care education, training, and access to medical supplies and equipment; staff training and educational needs; and important documentation, resources, literature and websites.

Key Interviews are as follows: Luanne Maki, FWFN, Community Health Representative, was the dominant participant in providing insight on the time line as she was contacted several times and provided constructive information on every aspect of the time line questions. Karen Bannon, FWFN, former Health Centre Manager, was contacted on occasion in regards to providing information on her employment experience with Dilico Home and Community Care as well. Marcella Kudaka, Home and Community Care Services Manager, was contacted and interviewed by Tom Grinnell, former Aboriginal Community Facilitator, which provided insight on her experience with palliative care education, training and needed equipment.

Resources:

Fort William First Nation website
Luanne Maki, FWFN, Community Health Representative
Karen Bannon, FWFN, former Health Centre Manager
Marcella Kudaka, Dilico, Home and Community Care Services Manager
Tom Grinnell, Lakehead University, former Aboriginal Community Facilitator