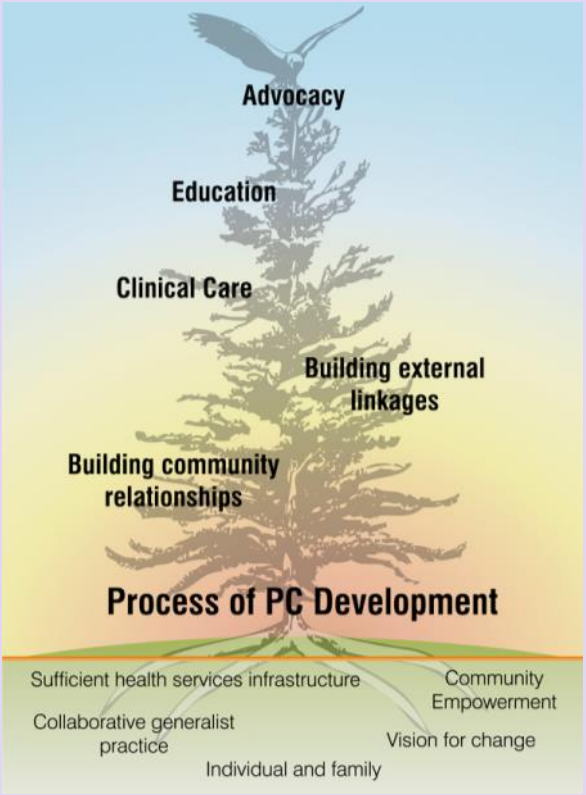
SIX NATIONS
LONG TERM CARE/
HOME AND COMMUNITY CARE



PALLIATIVE CARE PROGRAM GUIDELINES

519-445-0077

HOURS OF OPERATION
8:30 am—4:30 pm
Monday - Friday

Disclaimer

This palliative care program guideline booklet was developed as a guide to help those preparing for their final days by the Six Nations Palliative Care Leadership Committee. Information presented is based on current resources and is not meant to endorse any particular listing.

Haudenosaunee Philosophy Statement

Traditional philosophical principles have a crucial relevance to the challenges our people face today. Ohenton karihwatehkwen or the words that come before all else are a reminder of the place that we as human beings were meant to occupy in relation to all of Creation; a place of balance and respect. Our worldview comes from the Creation Story, the Original Instructions and is expressed in our annual cycle of ceremonies of thanksgiving. Our worldview teaches us that we exist with purpose, with a sacred intent and a duty to uphold the human responsibility to all of Creation. Our core philosophy is simply expressed as one body, one mind, and one heart. In the Haudenosaunee tradition, acceptance comes from a view of the natural order that accepts and celebrates the co-existence of opposites; our purpose is contained in the quest for balance and harmony, and peace is gained by extending the respect, rights, and responsibility of family relations to other peoples. The values are the state of peacefulness, the proper way to maintain peace, and the friendship and trust needed between all things for respect to prevail. In the words that come from the Thanksgiving Address “we must see the cycle of life continue” -and ensure the health and wellness of the people.

Mission Statement

Six Nations Health Services is dedicated to ensuring that each individual is respected and treated as a valued human being by providing, promoting and protecting and advocating holistic health home and community care services for current and future generations of the Six Nations Community.

Vision

To provide compassionate, coordinated, and comprehensive end of life care to individuals living in the community of Six Nations.

Terms

The Community Team will help facilitate the coordination of services as follows:

1. Provide a forum for information sharing and promote collaboration amongst team members.
2. Through information sharing, identify issues and/or deficiencies requiring attention and discussion. Team will then troubleshoot together and come up with solutions that work for everyone.
3. Maintain communication with appropriate networks of care and community partners.
4. Support and share educational opportunities for all involved (professionals' education including family and caregiver).
5. Promote the team as a resource to be accessed by the public/promote awareness of the team at the local level (public education).
6. Evaluate the program/process on a continuous basis, in order to make adjustments and improve upon the delivery of end of life care in the community.
7. Inclusion of Haudenosaunee Philosophy and maintaining cultural sensitivity in all decisions for the best interest of the people.

Six Nations Palliative Care Program
Path of Care

1. Referrals will be received for the Six Nations Palliative Care Program from all access points including hospitals, families, family health teams, cancer clinics and CCACs. In order for a patient to be followed by the Outreach physician for pain and symptom management, a physician referral is needed Anyone can refer to the Outreach team for psychosocial/bereavement support and do not need to be followed by a nurse/physician if family physician chooses to maintain primary responsibility of care. Clients will be determined to be palliative based on the response to two palliative care questions:

    a) Would you be surprised if client were to die within the year = NO
    b) Does the client have pain and symptom issues related to end of life = YES

Admission to the program does not need to be by physician alone. Any care provider who identifies an individual who could benefit from end of life care can discuss this with the individual and initiate the referral. Clients are admitted directly to CCAC and acute nursing agency (First Nations/Care Partners/Red Cross) and the Six Nations Long Term Care/Home and Community Care Program.

2. An initial home visit is made by the CCAC Palliative Case Manager and the LTC/Home and Community Care Case Manager and whoever else the family wants present. As well an initial referral could also be made by the Clinical Nurse Specialist and physician if a referral to CCAC has not yet been made.

    a) A palliative RAI assessment is completed and shared between each Case Manager and the appropriate consent is signed.
    b) Appropriate palliative services are initiated and equipment put in place. Client and family are given the contact information to ensure that they can access assistance on a 24/7 basis. The end of life checklist is put in the home. Clinical Nurse Specialist and Outreach Physician will make initial visit with patient and family.
    c) A pamphlet describing the program and related services is given to the client and family by Outreach Team and/or LTC/ H&CC CM, whoever makes initial contact. Information on “who to call” is left with the family i.e. acute nursing agency number.

d) The acute nursing provider (FNN/Care Partners/Red Cross) collaborates with the Outreach Team regarding plan of care (i.e. PPS, ESAS) and when to contact the Palliative Outreach Team.

3. CCAC Palliative Case Manager, Six Nations LTC/H&CC Case Manager, family physician or Oncologist initiates a referral to the Six Nations Shared Care/Outreach Team in association with the Brant Stedman Hospice Shared Care/Outreach Team.

   a) CCAC Palliative Case Manager facilitates a Physician (Family doctor) to Physician (Palliative Outreach Physician) referral based on the following priority scale:
      - Crisis Intervention—needs to be seen in 24 hours
      - High Risk—needs to be seen in 3 days
      - Moderate Risk—needs to be seen in 7 days
      - Minimal to No Risk—needs to be seen in 1 month

   b) The Stedman Community Hospice Referral Form is completed requesting the following:
      - Outreach team with clinical nurse specialist
      - Psychosocial /spiritual clinician
      - Bereavement service
      - Day program

4. Ongoing care – making sure that the client's care is comprehensive, seamlessly integrated, and monitored on a regular basis.

   a) Identification of the clinical team
      - Case Manager maintains a list of all service providers (physician, volunteers, nurses, homemakers, counsellor, clergy) who are involved in the care of the client. A Care Team Directory is put in place in the CCAC folder placed in the client's home. (names can be added by service provider as more HCP's become involved in care).
      - A roster of all palliative care clients will be maintained with the consent of the client and forwarded to all managers and physicians for collaboration and consultation.
      - The Six Nations Clinical Nurse Specialist will complete electronic charting on the Info Anywhere system that would see data maintained at the Stedman Hospice/Six Nations Outreach Team data base. Info anywhere is a web based site and accessible anywhere that there is internet service.

b) Common chart (a.k.a. CCAC in-home chart)
   - Can only be used in homes where there is an identified caregiver.
   - CCAC Case Manager must ensure that the individual and the family, and all other care providers coming into the home, are educated on the chart and encouraged to use it.
   - Expected Death in the Home forms i.e. Plan of Treatment Regarding Cardiopulmonary Resuscitation and Nursing Record Pronouncement of Expected Death at Home are put in place and discussed with client and family by CCAC Palliative Case Manager. A copy of the DNR will be forwarded to the LTC/H&CC CM who will advise PSS Supervisor and other staff as appropriate.

c) Case conferencing
   - A case conference may be called by any member of the clinical team at any time, in order to gather a patient's providers together to discuss any issues arising from their care.
   - The CCAC Palliative Case Manager and the Six Nations Clinical Nurse Specialist will attend regular palliative rounds at the Stedman Hospice/Six Nations according to the physician's schedule i.e. bi-weekly on Friday afternoon and monthly case management rounds.
   - A summary of the issues discussed during the case conference will be written up and distributed to all members of the clinical team, including those unable to attend the meeting.

d) Communication between hospital & community
   - The individual/family/service provider/physician will be encouraged to advise the CCAC Palliative Case Manager and/or the LTC/Home and Community Care Case Manager when the palliative client is admitted to hospital. Services will then be put on hold and the appropriate facility will be contacted to request notification when the client is discharged.
   - Prior to the individual returning home, a CCAC Case Management assessment will be completed and information with new orders will be forwarded to the CCAC/ Six Nations Palliative Care team.
   - Where there is no family physician, the Outreach physician will follow client through hospital stay.

5. Planning for an Expected Death in the Home (EDITH)

a) Case Manager follows CCAC's EDITH protocol to make the arrangements with the individual/family.
b) In conjunction it will be all Case Managers responsibility to make sure that all processes are in order to support EDITH. Case Manager will notify each member of the clinical team that an in-home death is being planned for.
c) The team will be aware of the client and family's wishes regarding the timing for follow up meetings, debriefing and removal of equipment (ten day wait period after death if family requests).

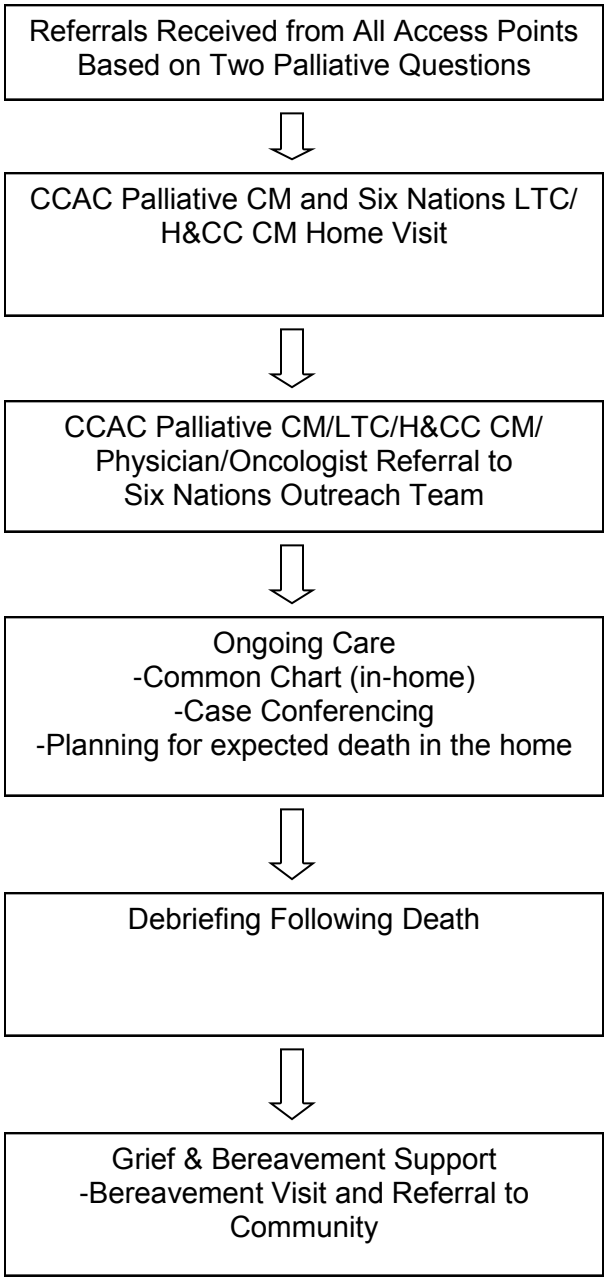
6. Debriefing Following Death

a) In the event of a sudden, tragic, difficult or emotionally draining death or where there is family conflict, a debriefing will be coordinated by the Case Manager and everyone who had a part in the client's care (the clinical team) will be invited.
b) Case Manager makes a bereavement visit to the family/ caregiver prior to the debriefing with consent from the family, to find out what worked and what didn't. Any important issues identified by the caregiver/family will then be discussed at the debriefing.
c) Notes will be taken during the debriefing to maintain a record of the issues that were discussed, and any possible solutions and/or program modifications that were suggested. These notes may be later used to identify common challenges/ barriers that need to be addressed at the Leadership Committee level.

7. Grief & Bereavement Support

a) The Six Nations Psychosocial/Spiritual/Bereavement Clinician completes one bereavement visit to the family/ caregiver (prior to the debriefing), within 2 weeks following the death of the individual.
b) The Six Nations Psychosocial/Spiritual/Bereavement Clinician makes a follow-up phone call one month following the death, to check up on the family and see how they're doing. If further support is needed, the family/caregiver can be provided with a list of bereavement services offered in the community and/or refer them to New Directions Community Counselling Group. There will also be a variety of grief and bereavement resources provided by the local Funeral Homes at specified locations in the community that can be accessed by the public.

Six Nations Palliative Care Program
Path of Care Flow Chart



Six Nations Palliative Care Program
List of Services

CASE MANAGEMENT UNIT

The Case Management Unit consists of 4 Case Managers who provide Intake and Referral for the services of the Long Term Care/ Home & Community Care program.

The Case Managers conduct an in depth assessment of a community member's health and functional ability and refers to the appropriate service provider on and off the Reserve.

They also attend family meetings, case conferences and hospital discharge meetings to ensure Six Nations residents understand the way our services operate and the limitations with our home care services. Once again to ensure client safety when sent back into the community setting.

Services Provided are:

- To provide intake and referrals for all clients
- To conduct needs assessments
- Determine clients plan of care
- To advocate for clients and ensure needs are met
- To liaison for clients with other agencies

REGISTERED NURSE

There are two complex care nurses who perform dual roles of visiting clients in the community who require maintenance care. One of the nurses provides foot/nail care for clients and provides hands on nursing when required.

Services provided are:

- Provides nursing care to clients' in the community
- General health monitoring
- Advocates for client to access services
- To help improve quality of life

PHYSIOTHERAPY

Physiotherapy promotes wellness, mobility and independent function. Physiotherapists understand how the body moves, what keeps it from moving and how to restore function.

Physiotherapy can help:

- Manage sprains and strains of joints and muscles
- Maintain your independence
- Recover after surgery
- Maximize your mobility
- Manage the physical complications of cancer and its treatment
- Pre-and post natal care and other women's conditions
- Manage conditions such as arthritis, neurological disorders, cardiac and respiratory disorders.

The physiotherapy treatment may include some or all of the components listed below:

- Therapeutic exercises
- Education about your condition
- Hands on manual therapy techniques
- Posture and gait retraining
- Electrical modalities and acupuncture

Physiotherapy services are available on the first floor of the White Pines Wellness Center.

OCCUPATIONAL THERAPY

The Occupational Therapist is available on Mondays and Wednesdays.
The OT receives new referrals at that time and makes visits to clients in the community requiring equipment.

The OC provides assessment and treatment related to:

- Environment and safety assessment
- Body mechanics in the home
- Education of lifting and carrying techniques
- Promote independence in the home
- Energy conservation techniques
- Pain management
- Relaxation
- Referral to community resources
- Training in the activities of daily living
- Use of devices and adaptations
- Mental health rehabilitation
- Life skills
- Assists in accessing funding through various programs such as ADP, RRAP, and NIHB
- Assesses transfer techniques and mobility issues.

ADULT DAY CENTRE

Assessment:

- Clients are assessed by the case manager to determine eligibility
- Adjuvant to conduct a leisure inventory profile with client and/or family
- Day center/team to develop an individual program plan for the client to outline goals and objectives for programming

Transportation

- Transportation is arranged by the caregiver or family member for the client

Client cost for the program

- Lunch is available from Meals on Wheels
- Monetary donations accepted
- Drinks and snacks are available
- Special events may carry an additional charge

NUTRITIONIST/DIETITIAN

The Long Term Care Dietician provides in home visits and office visits to set up meal plans and provide nutritional surveillance to clients requiring assistance with a variety of diagnoses ranging from diabetes to weight loss to renal to palliative. The dietician also acts as an integral member with Health Promotions.

Services provided are:

- Nutrition/Dietary Counselling—available for one-to-one counselling, with family members or for groups
- Group Presentations—possible target groups: toddlers, preschoolers, teens, adults and seniors. Any nutrition related topic may be covered upon request
- Diabetes Education Program
- In-School Curriculum—Diabetes Awareness and Prevention is taught in all schools twice a year
- Educational Resource—written and audio visual materials are available to the community covering numerous areas

COMMUNITY SUPPORT SERVICES

The Six Nations Community Support Services offers many different services to seniors (65+) and disabled person who are residents and registered band members of the Six Nations of the Grand River

Services provided are: (some services may have a minimal monetary fee)

- Meals on Wheels—delivery of a hot nutritious meal to clients home five days per week
- Transportation—every Monday and Friday transportation (van) to local centers for purposes of shopping and banking. A courier service is available
- Home maintenance and repairs
- Home help-workers—provide light housekeeping services such as vacuuming, mopping floors, laundry, dishwashing and dusting
- Friendly visiting— workers will visit seniors in their homes in order to keep them socially involved in community events and news
- Security—workers will make regular telephone contact to seniors' in their homes
- Diners club—supervised recreational and social group activities (Silver Fox Club) are offered every Tuesday and Thursday at a setting location. Transportation and meals are provided

SPEECH SERVICES

Speech Services helps clients to overcome and prevent communication problems and difficulties with swallowing. Communication difficulties in the areas of language, speech, voice, fluency may involve producing sounds, words and sentences; understanding or listening to the speech of others; and the use of reading and writing skills (literacy).

Services provided are:

- Assessment and management of speech and language, feeding/ swallowing difficulties
- Set treatment goals with family and caregivers, determine and provide care plans to meet these goals
- Develop and monitor programs to be carried out by other care providers (including Communicative Disorders Assistants)
- Provide consultation, individual or group therapy in clinic or in the home
- Collaborate with Physicians, Nurses, Dietitians, Teachers, Psychologist, Occupational Therapists, Educational Assistants, Personal Support Workers and other care providers

Caring for People with Communication Disorders

HEALTH ADVOCACY OFFICE

This service provides a holistic assessment in regard to issues such as financial, legal, personal, emotional and/or mental needs of the client.

Services provided are:

- Public presentations and trainings
- Supportive counselling e.g. survivors of heart attacks, strokes and dementia
- Supportive counselling of issues or concerns of Elder abuse
- Palliative care counselling for clients and caregivers
- Counselling related to aging process
- Advise on financial needs
- Navigate for services with health and social issues

PERSONAL SUPPORT SERVICES

Personal support services are provided to all Six Nations band members of all ages based on individual needs per the Case Manager's nursing assessment.

Services provided are:

- **Personal care—**assistance in personal hygiene, bathing, dressing, grooming, toileting and transfer assistance.
- **Meal planning/preparation—**assistance with grocery lists, grocery shopping, planning and preparing meals, special diets
- **Ambulation—**assisting with ambulation in wheelchairs, assistance with walkers, canes, transfers and safety supervision
- **Exercise—**assisting with a planned medical regime under the supervision of a physiotherapist
- **Respite care—**providing care giver relief
- **Home Management—**assisting with light housekeeping
- **Personal business—**assisting with banking, bill paying and sending/receiving mail, accompanying clients to medical appointments
- **Child care—**providing child care while the primary giver is ill/ incapacitated/convalescing
- **Advocacy—**assisting with referrals to additional agencies for other services

SUPPORTIVE HOUSING
JAY SILVERHEELS COMPLEX

The Jay Siverheels Complex provides supportive care for Onkwehonwe who have experienced a spinal cord injury the opportunity to move back to Six Nations. The potential clients will be able to return to their own community to live in one of the 8 specially equipped apartments located in Ohsweken. We also provide short term respite to any Six Nations band member. We have designed a spacious environment with the client's needs in mind.

Services provided are:

- Semi-private roll in shower
- Special lifts which run on a ceiling track
- 24 hour personal support workers on site
- Meals provided daily by qualified personnel and served in a spacious dining area

All applicants will go before an Admissions Committee and prioritized according to Supportive Housing criteria.

TRADITIONAL WELLNESS COORDINATOR

The Traditional Wellness Coordinator role is:

- Promote concepts of traditional health
- Organize or assist with implementing traditional teachings and activities
- Resource development
- Assisting the needs of clients referred for care
- Identify & coordinate resource people to assist individuals or families in need of traditional healing
- Networks with culturally knowledgeable people & other Traditional Healing programs.

TRADITIONAL KNOWLEDGE CARRIER

The Haudenosaunee are inseparably connected to the land and its resources. The knowledge, language, stories, and ceremonies are intertwined between the land and the people. Traditional knowledge encompasses all knowledge pertaining to the Haudenosaunee and their territory and has been transmitted from generation to generation.

Knowledge teaches the people how to be responsible for their own lives and develops their sense of relationship to others. The Traditional Knowledge Carrier is an individual who is recognized by their community as having knowledge and understanding of the traditional cultural practice of the community, including the language, spiritual and social practices.

The Traditional Knowledge Carrier works with the people towards the restoration of balance and harmony to the body. The diverse elements of the Haudenosaunee can be acknowledged, learned, and understood by means of the teachings shared by a culturally knowledgeable person.

Six Nations List of Health Services

Ambulance 519-445-4000
Dental Services 519-445-2221
Early Childhood Development 519-445-0339
Family Health Team 519-445-4019
- Primary Health Care

Health Administration 519-445-2418
- Clinic Nurse
- Medical Receptionist
- Medical Transportation
- Public Health Receptionist
- School Nurse
- Sexual Health Nurse

Health Promotion & Nutrition Services 519-445-2809
- Activity Program
- Diabetes Education
- Healthy Lifestyles
- Nutrition Counselling

Healthy Babies/ Healthy Children 519-445-1346
Iroquois Lodge 519-445-2224
Long Term Care 519-445-0077
- Adult Day Care
- Community Support Services
- Home & Community Care/ Case Management/Equipment
- Jay Silverheels Complex
- Personal Support Services
- Professional Services/Part Time Driver

Mental Health Team 519-445-2143
- Case Management
- Early Intervention in Psychosis
- Mental Health Educator
- Psychiatric Consultation
- Rehabilitation Services
- Release from Custody
- Supportive Housing

New Directions Group 519-445-2947
- Addiction Counselling/Bereavement Counselling
- Addiction Outreach Worker
- Animal Control
- Community Health Rep.

Share-AP 519-445-2226
Six Nations Maternal & Child Centre 519-445-4922
- Aboriginal Midwives
- Breastfeeding Coordinator
- Children's Health Services
- FASD Coordinator

Contact Information for the Longhouses

Haudenosaunee Resource Center
905-765-1749

Casket Maker

Two Feathers 519-933-6922
Hills Custom Coffins 519-861-0370

Cooks

Janice Henry 905-768-1945
Virgie General 519-445-0904

Clothing

Iroqrafts 519-445-0414
Martins Crafts 519-445-2558

Moccasins

Deanna Sky 519-445-2472
Wanda Green 519-445-2920

Corn Bread

Sky's Corn 905-765-5050
Hill's Native Food 519-445-2390

Wake Singers

Cam Hill 905-765-1749

Speakers

Onondaga, Mohawk, Seneca
- Pete Sky 519-445-2933

Cayuga, Tuscarora, Oneida
- Leroy Hill 905-765-6866

Contact Information for the Local Churches

- Bethany Baptist 519-445-0561
- Chapel of the Deleware United 905-768-1366
- Faith Victory Tabernacle 519-445-2691
- Grand River United 519-445-0955
- Johnsfield Baptist 519-445-2872
- Medina Baptist 519-445-4396
- Ohsweken Baptist 519-445-2908
- Six Nations Pentecostal 519-445-4291
- Six Nations Seventh Day Adventist 519-770-4585
- St.Peter's St.Luke's, St.Paul's, Christ Church—Anglican 519-445-2661

Funeral Homes:

- Styres Funeral Chapel: Ohsweken 519-445-2262
- Hyde & Mott Chapel: Hagersville 905-768-5733
- RHB Anderson Funeral Homes LTD
    - Tel#: 905-768-5733
    - Fax#:905-768-2724
    - E-mail: rhbanderson@mountaincable.net

Client Bill of Rights

CLIENT RIGHTS

Every Client has the right to:

- Be treated with courtesy and respect
- Have one's own ethnic, cultural spiritual and religious values respected
- Have information about the organization that is providing services and how those services are to be provided
- Give consent to, or refuse service or treatment
- Confidentiality with respect to their personal or medical information
- Raise concerns and recommend changes regarding service delivery
- Have information on where and how to direct grievances or concerns regarding service or service providers
- Participate in the scheduling of visits with case manager to accommodate (when possible) conflicting dates and times
- Have the level of service assessed and adjusted according to treatment plan; with plan towards discharge if possible

CLIENT RESPONSIBILITIES

Every client has the responsibility to:

- Treat service providers with courtesy and respect
- Expect ethnic, cultural and religious values be recognized by service providers
- Provide all required information and sign the needed consents in order to receive services
- Be involved in care planning and follow a mutually agreed upon plan
- Inform care provider of any change in condition or needs (hospital, holiday) as soon as possible
- Accept the scope and limitations of service providers
- Make every effort to be as independent as possible
- Be present and prepared for the service providers visit
- Give the service provider as much notice as possible when you need to cancel a visit

Statement of Information Practices

Collection of Information

We collect personal health information (PHI) about you directly from you or from a person acting on your behalf. The personal health information that we collect may include: your name, date of birth, address, health history, band number, record of your visits, and the care that your received during those visits. Occasionally, we collect personal health information about you from other sources, if we have obtained your consent to do so or if the law permits.

Uses and Disclosures of Personal Health Information

- Treat and care for you
- Plan, administer and manage our internal operations
- Conduct risk management activities
- Conduct quality improvement activities
- Compile statistics
- Conduct research
- Teach
- Conduct client satisfaction surveys

Your Choices

You may withdraw your consent for some of the above uses and disclosures by contacting us and completing a Withdrawal of Consent Services for PHI Use Form.

Important Information

We take steps to protect your personal health information from theft, loss and unauthorized access, copying , modification, use and disclosure, and disposal. We conduct audits and complete investigations

If you think we have violated your rights, contact the:

Information & Privacy Commissioner/Ontario
2 Bloor Street East, Suite 1400
Toronto, ON M4W 1A8
1-800-388-3333

Dedicated to the memory of Christine Sky,

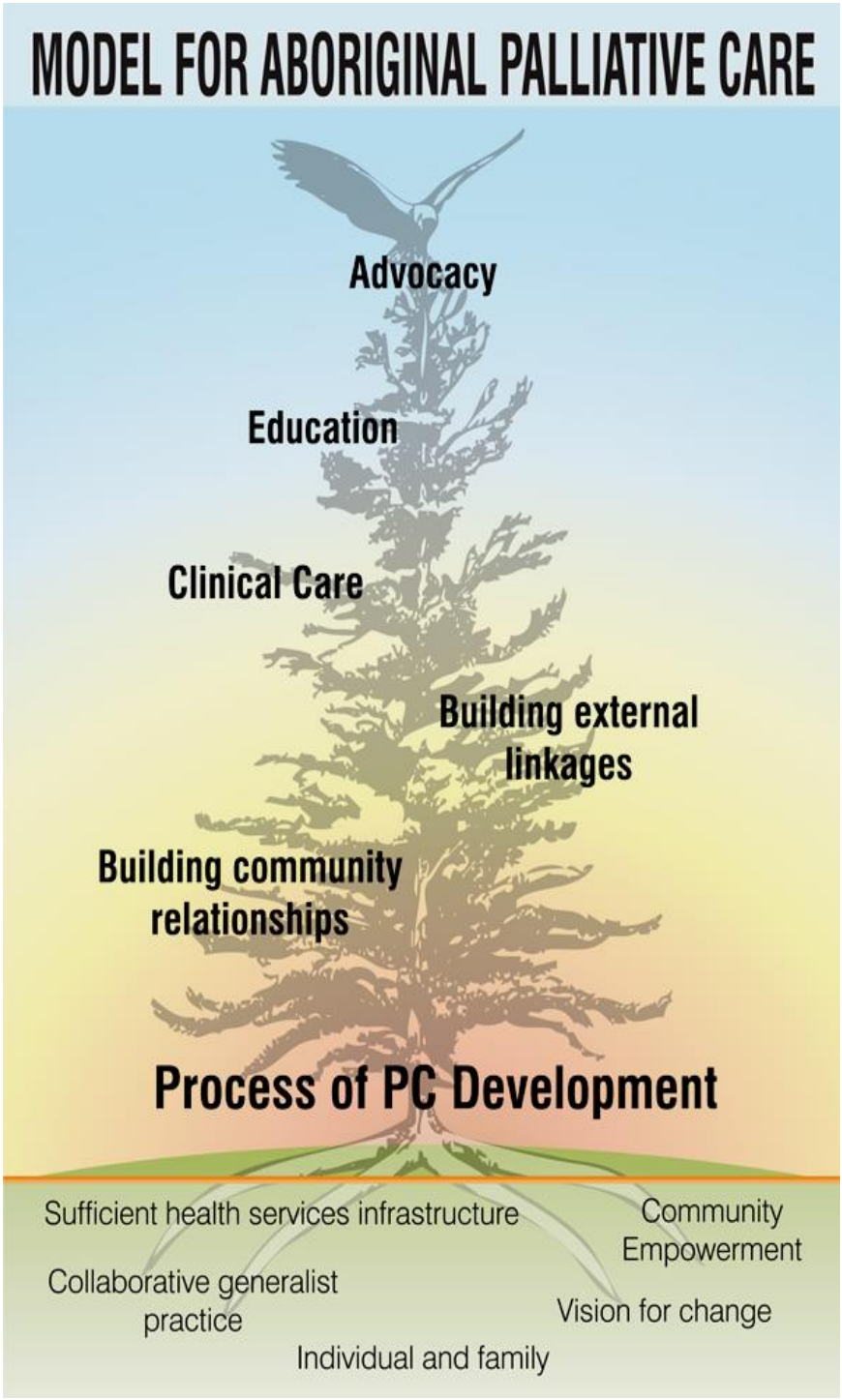
our Traditional Knowledge Carrier,

who assisted in the development of our resources:

The Journey Back Home

and

For The One's Left Behind


MODEL FOR ABORIGINAL PALLIATIVE CARE
Advocacy
Education
Clinical Care
Building external linkages
Building community relationships
Process of PC Development
Sufficient health services infrastructure
Community Empowerment
Collaborative generalist practice
Vision for change
Individual and family