



**Family Caregivers
of British Columbia**

Coach Caregiver: Caregiver Insights into Palliative Care

Coach: Wendy Johnstone, Gerontologist

Guests: Katherine Arnup, Dr. David May & Christien Kaaij, Pat Porterfield

Host & Moderator: Janet McLean, Family Caregivers of British Columbia



**United Way
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Who We Are

- **Family Caregivers of BC (FCBC) is a non-profit charity dedicated 100% to the wellbeing of family caregivers.**
- **27 years, first of its kind in Canada.**
- **Serving BC since 2010, past 3 years with Ministry of Health Patients as Partners provincial funding.**
- **60% of Board members must have caregiving experience.**



CAREGIVER SUPPORT

Information, referral & navigation
1-1 Caregiver Coaching
Support Groups
Online Resource Centre

Call 1-877-520-3267
Call 1-877-520-3267 for referral assessment
Visit www.familycaregiversbc.ca for listing
Visit www.familycaregiversbc.ca for resources

EDUCATION

Online Resource Centre
Webinars & Workshops
Events & Presentations

Visit www.familycaregiversbc.ca for listing
Register @ www.familycaregiversbc.ca
Caregiver Connection Newsletter & eNews –
subscribe @ www.familycaregiversbc.ca

COLLABORATION & ENGAGEMENT

Health System Improvement
Participate in Research

Contact us to engage as a voice for family caregivers in the health care system

Learning Objectives

As a result of this Caregiver Coach webinar, participants will:

- Understand what palliative care is.
- Gain insight into the benefits.
- Learn when and how to access.
- Take away a list of reference materials for future exploration.

PLEASE participate – interact in the chat box or put your hand up to speak!!

Tonight's Coach



Wendy Johnstone

Wendy has a Masters degree in Gerontology and over 20 years of experience working with family caregivers and seniors.

In addition to her work with the Family Caregivers of BC, Wendy runs her own company in the Comox Valley called Keystone Elder Care Solutions.

Guest: Katherine Arnup



Katherine Arnup, PhD

Katherine Arnup is a writer, life coach, hospice volunteer, and a retired Carleton University professor.

She is the author of several books including her latest “I Don’t Have Time For This!” A Compassionate Guide to Caring for Your Parents and Yourself.

As a life coach, she provides compassionate, courageous support for people dealing with major transitions and for families and individuals dealing with aging, illness and end of life issues.

You can contact her @
katherine@katherinearnup.com

Guests: Dr. David May & Christien Kaaij



Dr. David May

David May has been a family doctor for 25 years. His areas of focus are palliative care and pain management, mental health, and anesthesia. He is the Board Chair of the Powell River Division of Family Practice, Collaborative Services Committee member, and sits on the mental health review panel board.

David has designed and teaches a palliative care and chronic pain module for physicians and registered nurses which he has implemented in Powell River.

Christien Kaaij is a Project Manager and Community Developer and has been supporting Dr. May with his palliative care project since April 2015.

Guest: Pat Porterfield



**Pat Porterfield,
RN, NS
Palliative Care**

Pat Porterfield has been involved in palliative care as a clinician, educator and researcher for over 35 years.

She retired from her position as Regional Leader for Palliative Care at Vancouver Coastal Health in 2012. While at Vancouver Coastal Health, she was involved with initiatives to extend a palliative approach into residential care and primary care, including participation in the development of an End-of-Life Module for General Practitioners.

Pat continues to educate for advance care planning and co-chairs the BC Centre for Palliative Care Advance Care Planning Public Awareness and Education Working Group.

Palliative Care Origins

- Inspired by the work of Cicely Saunders at St. Christopher's, Dr. Balfour Mount, a urologist and surgical oncologist, piloted a study on the needs of dying patients in Royal Victoria Hospital in Montreal in September 1973.
- He established a hospice-like ward within the hospital to relieve suffering and provide quality end of life care.
- He coined the term “palliative care” - the word “palliative” is derived from the Latin word *palliare* meaning “to cover or cloak” and an alternative to the word “hospice” which in French carries the stigma of a place of last resort for the poor and derelict.
- The pilot project featured “a consultation team to work with other hospital wards, a home-care outreach service, and a bereavement follow-up program.
- Dr. Mount is known as the father of palliative care in North America and has devoted himself to spreading the message of palliative care throughout his life.”

What is Palliative Care?

- Palliative care improves the quality of life of patients and their caregivers facing a life-threatening illness.
- It focuses on the prevention and relief of suffering by early assessment and treatment of pain and problems: physical, emotional and spiritual.



It intends neither to speed up or delay death.

What is Palliative Care?

- It focuses on care and comfort rather than cure.
- It consists of medical care combined with social, emotional and spiritual support.



- It is applied throughout the illness trajectory to help relieve suffering, improve the quality of life, engage people in their care, potentially prolong life and strive for a comfortable death.
- It can be provided in many settings: home, facilities and in-patient units.

What is Hospice Palliative Care?

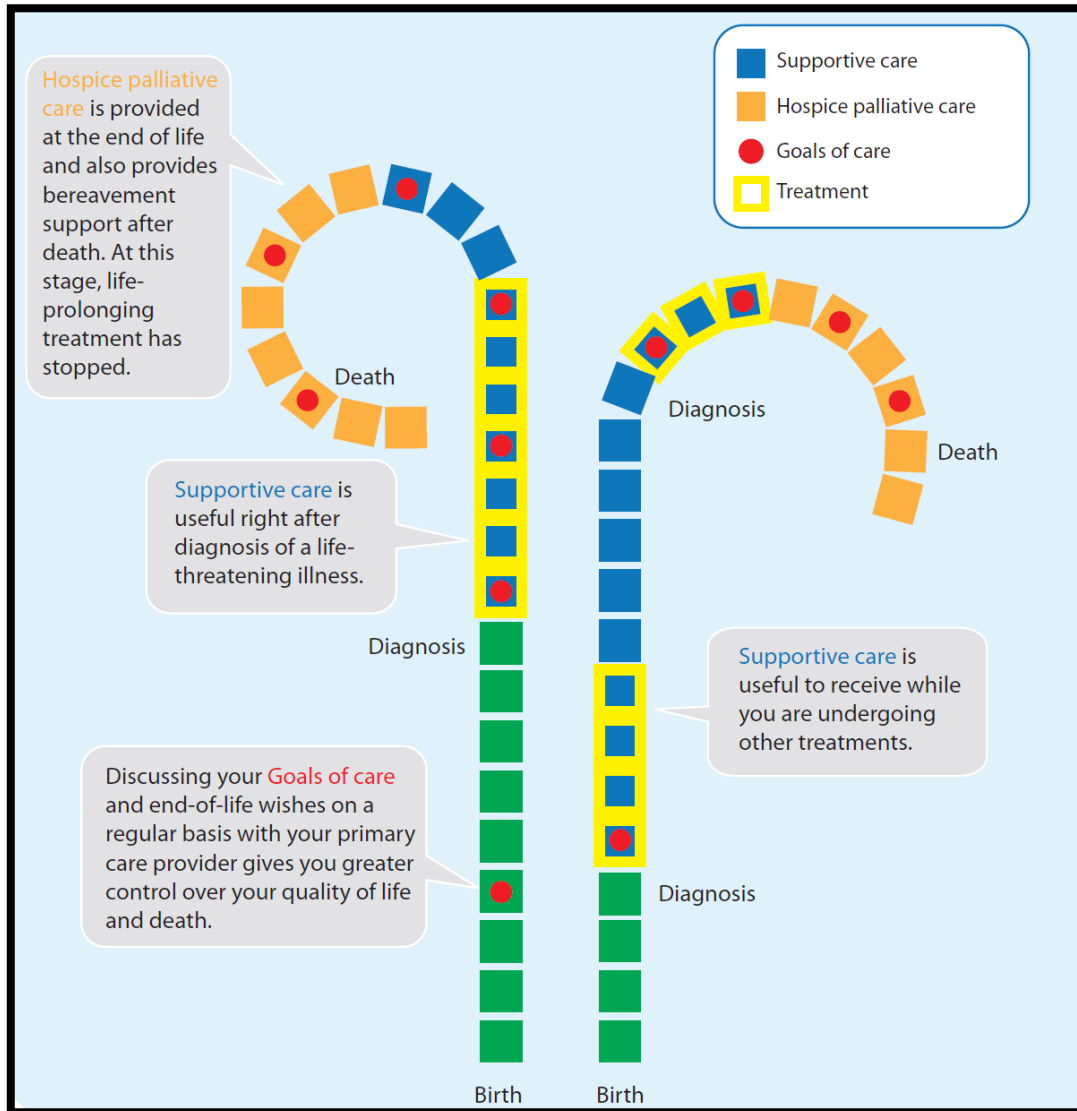
- Hospice palliative care is a term often used interchangeably with palliative care.
- The principles and norms of practice are the same - to relieve suffering and improve quality of life throughout the illness and bereavement experience, so patients and families can realize their full potential to live even when they are dying.
- The physical location of a "residential hospice" is usually a community-based facility.
- Hospice Societies across BC provide a wide variety of programs and services
<https://bchpca.org/>.

Is Your Loved One Palliative?

Does he or she have a life-threatening illness and...

- Symptoms that impact his/her activity level or quality of life
- Difficult side effects from treatments
- Needs help making medical decisions about treatment options
- Needs help coping with the stress

Two Life Journeys



All Care Support Program



Palliative Care Process

- Discuss with your care recipients physician.
- If the physician thinks your care recipient has a life expectancy of 6 months, a Palliative Care Benefits Program (PCBP) registration form will be prepared.
- Under PCBP – costs for equipment, supplies and drugs are covered.
- Be prepared for a visit from Home & Community Care.
- HCC will complete an “intake” and care plan outlining things like the frequency of visits.

Why It Matters

- Caregivers need to be aware of palliative care services.
- Needs change as illness progresses.
- Well-informed caregivers are better able to care for their loved ones and have a more positive experience.



What You Need to Know

Goals

- Your loved one's goals around care and treatment.
- It is important for health care providers to know your care recipient's wishes around quality of life and death.
- This will be an ongoing discussion with your primary care provider as palliative care works with regular treatment.

Information & Resources




- You need to know where to get information to ensure the best care for your care recipient.
- You need to know where to get support for YOU.

Topics to Explore

- How to communicate with your loved one's physician
- The illness trajectory
- Symptom management options
- Accessing health services
- Using medical equipment
- Compassionate leave, Advance Care Planning, legal services, etc.
- Caregiver coping strategies



Where To Go For Help

TOPIC	CONTENT	HELP
<p><i>How do I...?</i></p> 	Information and referral, community resources.	<ul style="list-style-type: none"> • Family Caregivers of BC Support Line: 1-877-520-3267 • Home Care Nurse, Social Worker
<p><i>What did the doctor mean?</i></p>	The medical picture; medication anxieties; myths about morphine; what “dying” looks like.	<ul style="list-style-type: none"> • Primary Care Physician • Health Care Specialists
<p><i>Wading through the legal stuff</i></p>	Wills, power of attorney, advanced directives, funeral planning, etc.	<ul style="list-style-type: none"> • Nidus website www.nidus.ca
<p><i>Am I going out of my mind?</i></p>	The LOSS and GRIEF you are experiencing takes a huge toll.	<ul style="list-style-type: none"> • Family Caregivers of BC Support Line: 1-877-520-3267 • Caregiver Support Group
<p><i>Am I doing this right?</i></p> 	Feeding, moving, handling, equipment...	<ul style="list-style-type: none"> • Home Care Nurse, Physiotherapist, Occupational Therapist
<p><i>What about ME?</i></p> 	What does this experience mean to me? Stress management & self-care.	<ul style="list-style-type: none"> • Family Caregivers of BC Support Line: 1-877-520-3267 • Social worker / Counsellor

Resources

BC Centre for Palliative Care

<http://www.bc-cpc.ca/cpc/>

BC Hospice Palliative Care Association

<https://bchpca.org/>

Canadian Hospice Palliative Care Association

<http://www.chpca.net/>

<http://www.chpca.net/family-caregivers/faqs.aspx>

Canadian Virtual Hospice

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

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

Change Foundation

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

Katherine Arnup – website

<http://katherinearnup.com/>

Nidus Registry

<http://nidus.ca>

Powell River Hospice Palliative Care Resource

<http://prhospice.org>

Speak Up Website – National Advance Care Planning

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

Support to Talk About End of Life Wishes

<http://theconversationproject.org>

Caregiver Questions



Caregiver Questions

- **What would be the benefits of Palliative Care?**
- **My partner is not ready for palliative care, as he/she is not dying yet.**
- **What do they do differently when people get Palliative Care, compared to regular care?**

Caregiver Questions

- Where would we get it?
- Isn't my physician already providing it?
- Don't they stop treatment when we get Palliative Care?
- Who pays for palliative care?

Webinar Action List

As a result of this webinar I will:

Start...

Stop...

Continue...

Visit www.familycaregiversbc.ca for additional resources on relevant caregiving topics.

Closing Comments



**Thank YOU
For Attending!**



Family Caregivers
of British Columbia

toll free 1.877.520.3267

www.familycaregiversbc.ca