

UVRA: End of Life Matters

Navigating Palliative Care Services



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ISLAND HEALTH: PALLIATIVE AND END OF LIFE PROGRAM

LEARNING OBJECTIVES

WAY IN



- **DEFINE** Palliative care
- **DIFFERENTIATE** Palliative care from hospice care
- **EXPLAIN** Why palliative care is important
- **DESCRIBE** The domains of palliative care
- **DISCUSS** Social aspects of care
- **IDENTIFY** Resources available to support caregivers

DEFINITION OF PALLIATIVE CARE

“PALLIATIVE CARE IS AN APPROACH THAT IMPROVES THE QUALITY OF LIFE OF PATIENTS AND THEIR FAMILIES FACING PROBLEMS ASSOCIATED WITH SERIOUS ILLNESS, THROUGH THE PREVENTION AND RELIEF OF SUFFERING BY MEANS OF EARLY IDENTIFICATION AND IMPECCABLE ASSESSMENT AND TREATMENT OF PHYSICAL, PSYCHOSOCIAL AND SPIRITUAL PROBLEMS”



DEFINITION OF HOSPICE

Is derived from the Latin word “hospitium”, which means hospitality. The first Hospices were places of hospitality for the sick, wounded, or dying, usually travelers and pilgrims. Today, the term is used to define programs that provide palliative care aimed at comfort to support those living with life limiting illness in a homelike setting.

Hospice care treats the person and symptoms of the disease, rather than treating the disease itself. Hospice care provides an alternative to therapies focused on life-prolonging measures when these are not aligned with a person's goals.



Palliative Care

VS

Hospice Care

Physical and psychosocial relief

Focus on quality of life

Multidisciplinary Team Approach

Any stage of disease

May be concurrent with curative treatment

Physical and psychosocial relief

Focus on quality of life

Multidisciplinary Team Approach

Prognosis 3-6 months or less

Excludes curative treatment



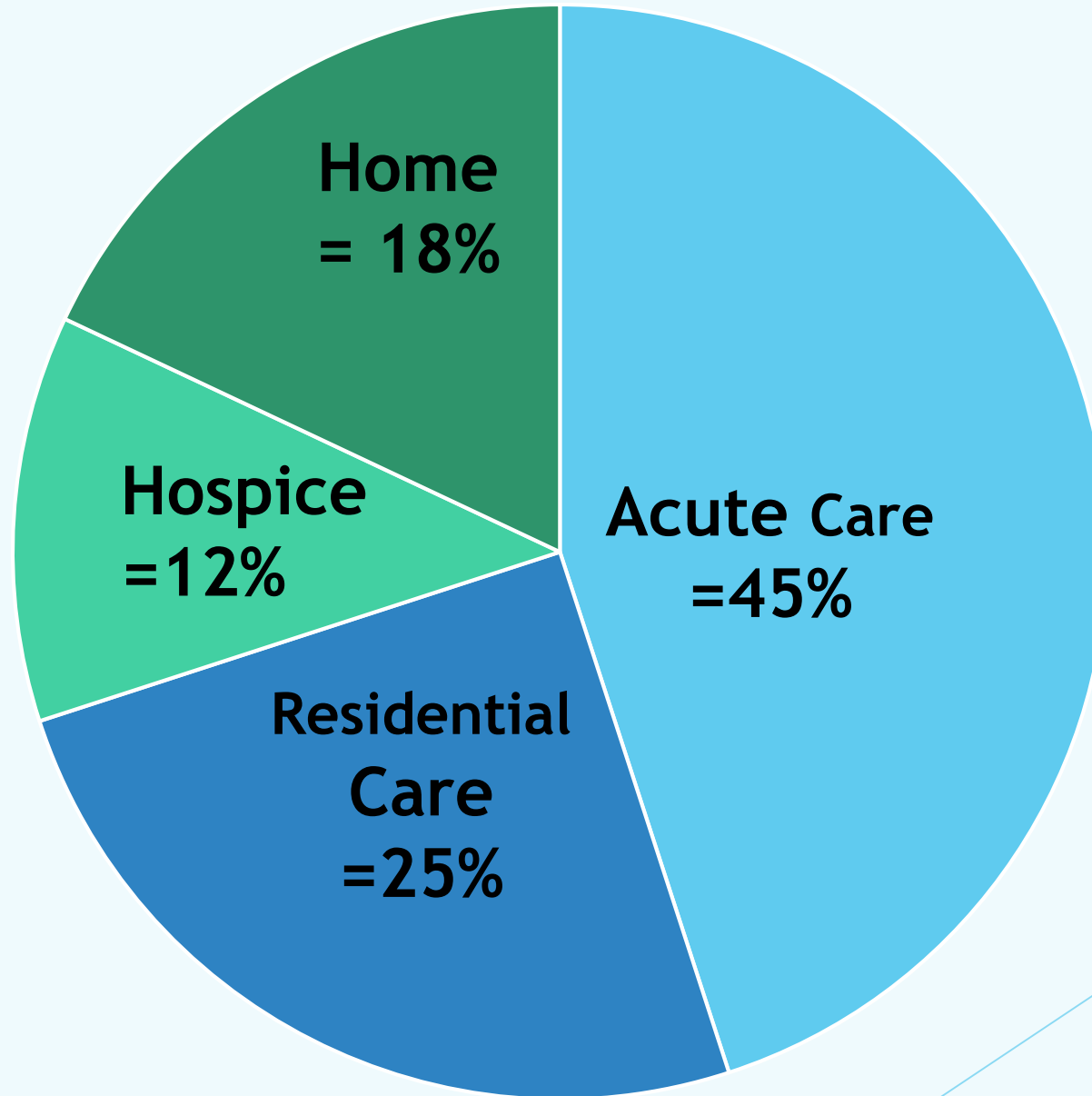
Elements of good palliative care

According to the [World Health Organization](#), palliative care

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families;
- Will enhance quality of life and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.



Deaths in Island Health

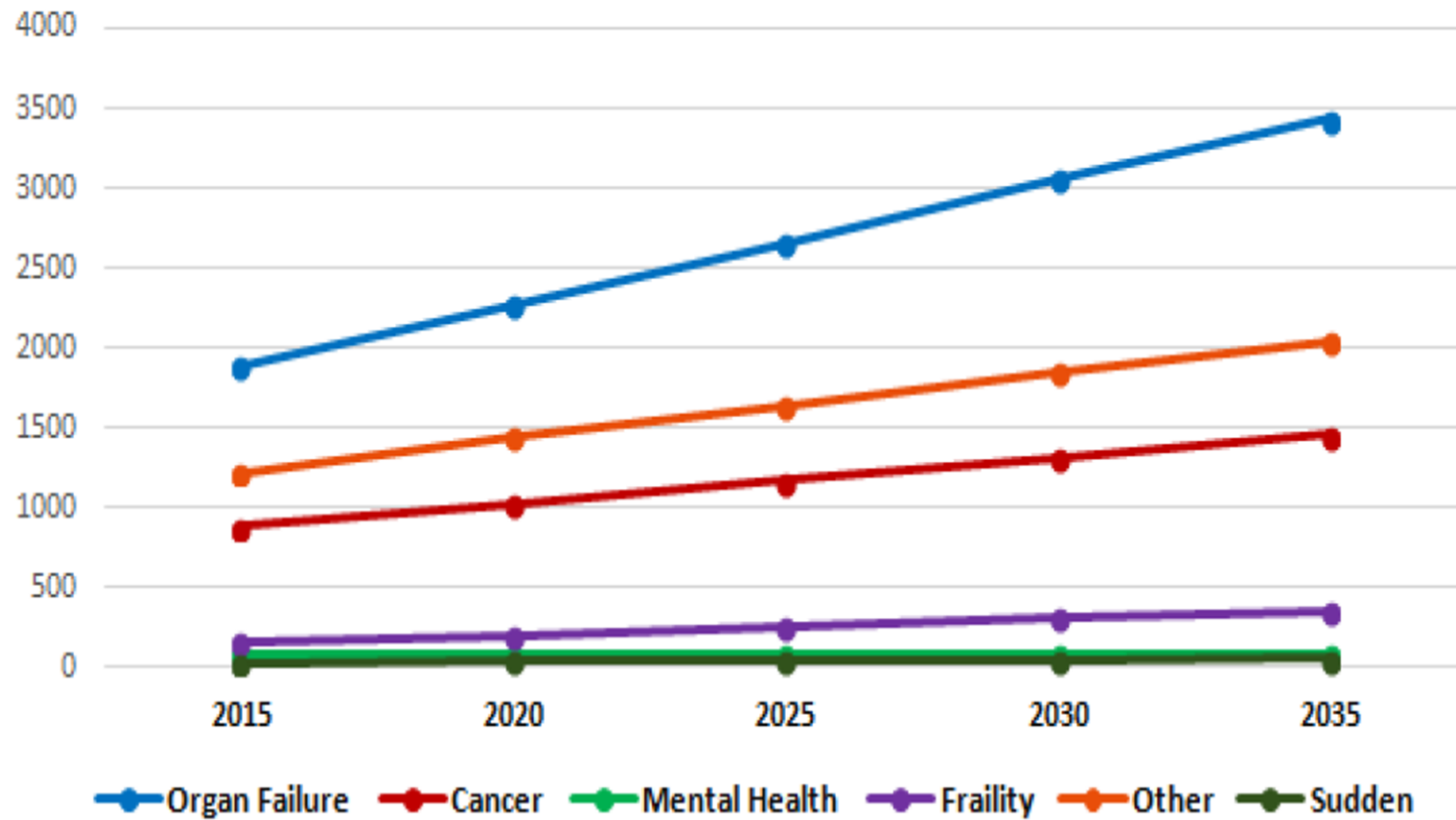


Dying is *not* a medical event

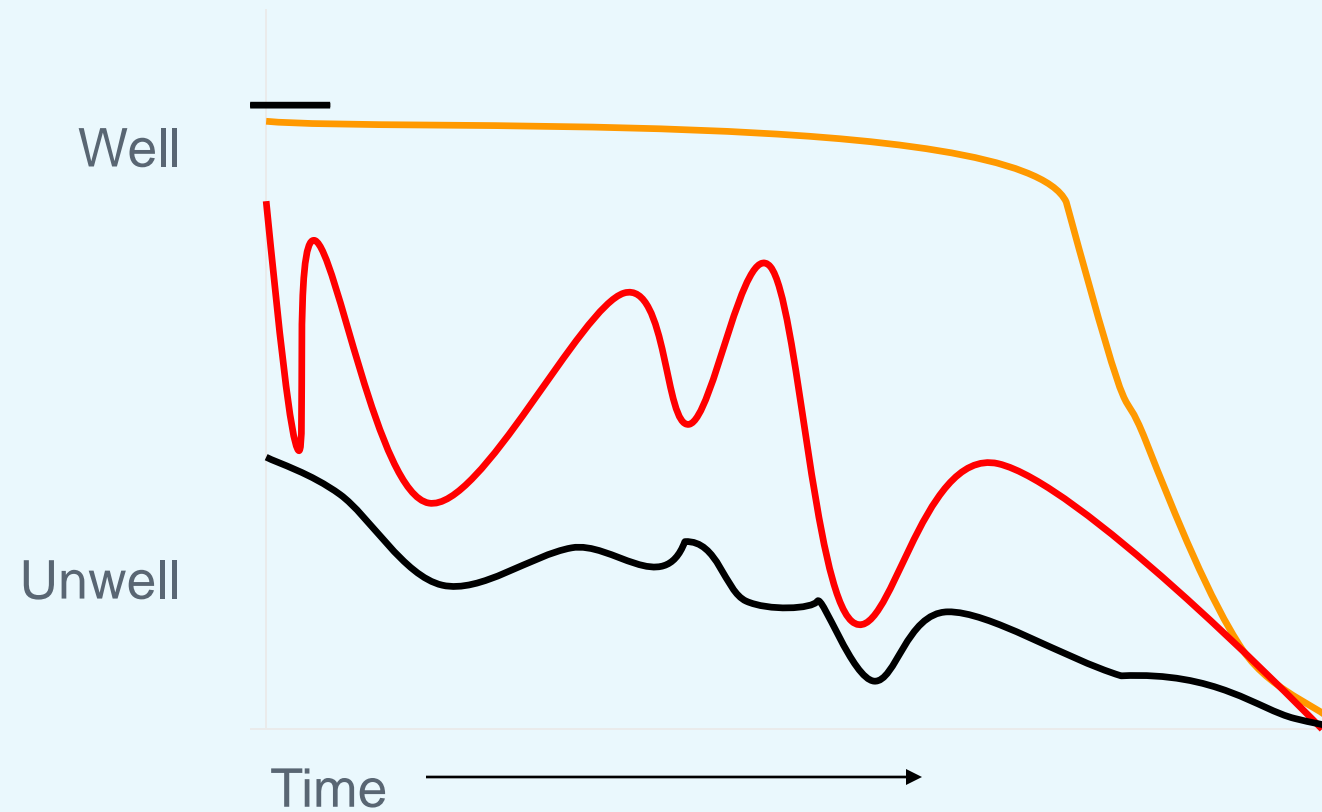


“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

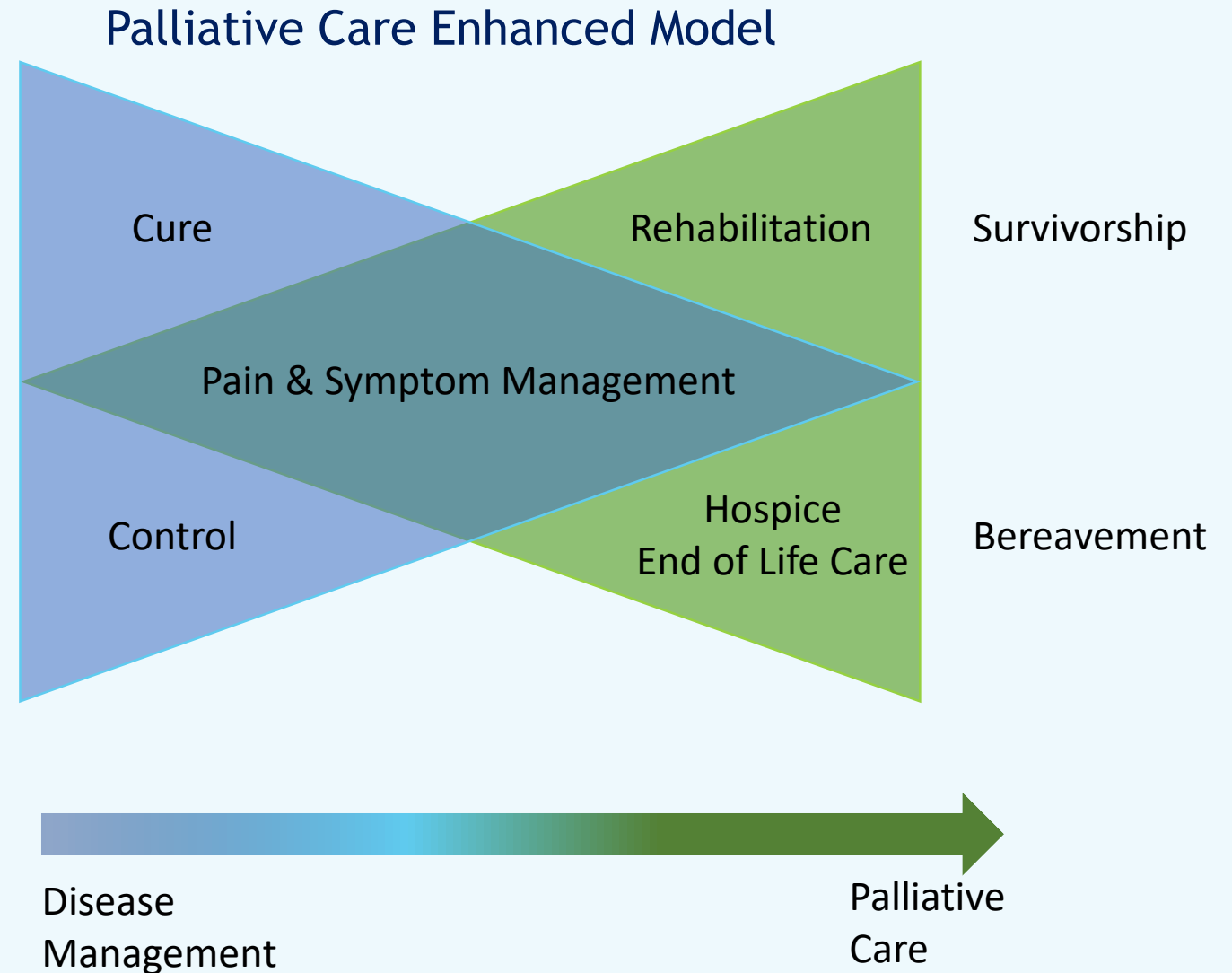
Projected Deaths by Trajectory on Vancouver Island



Trajectories of Living in the final phase

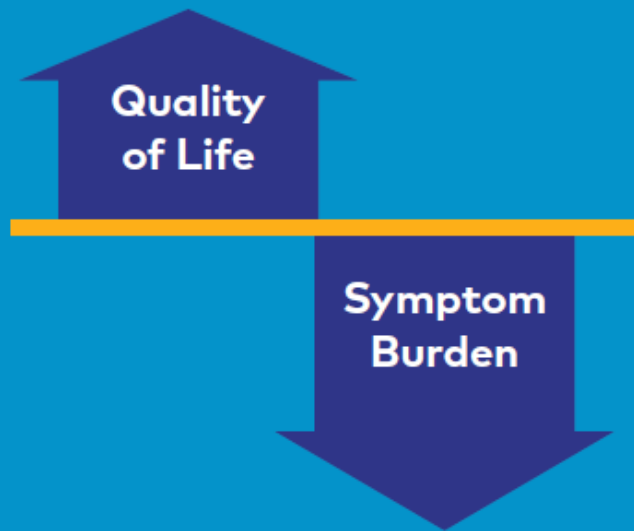


APPROACH TO PALLIATIVE CARE



Palliative Care Improves Quality of Life

IMPROVES QUALITY OF LIFE
AND SYMPTOM BURDEN



Reduces symptom
distress by

66%

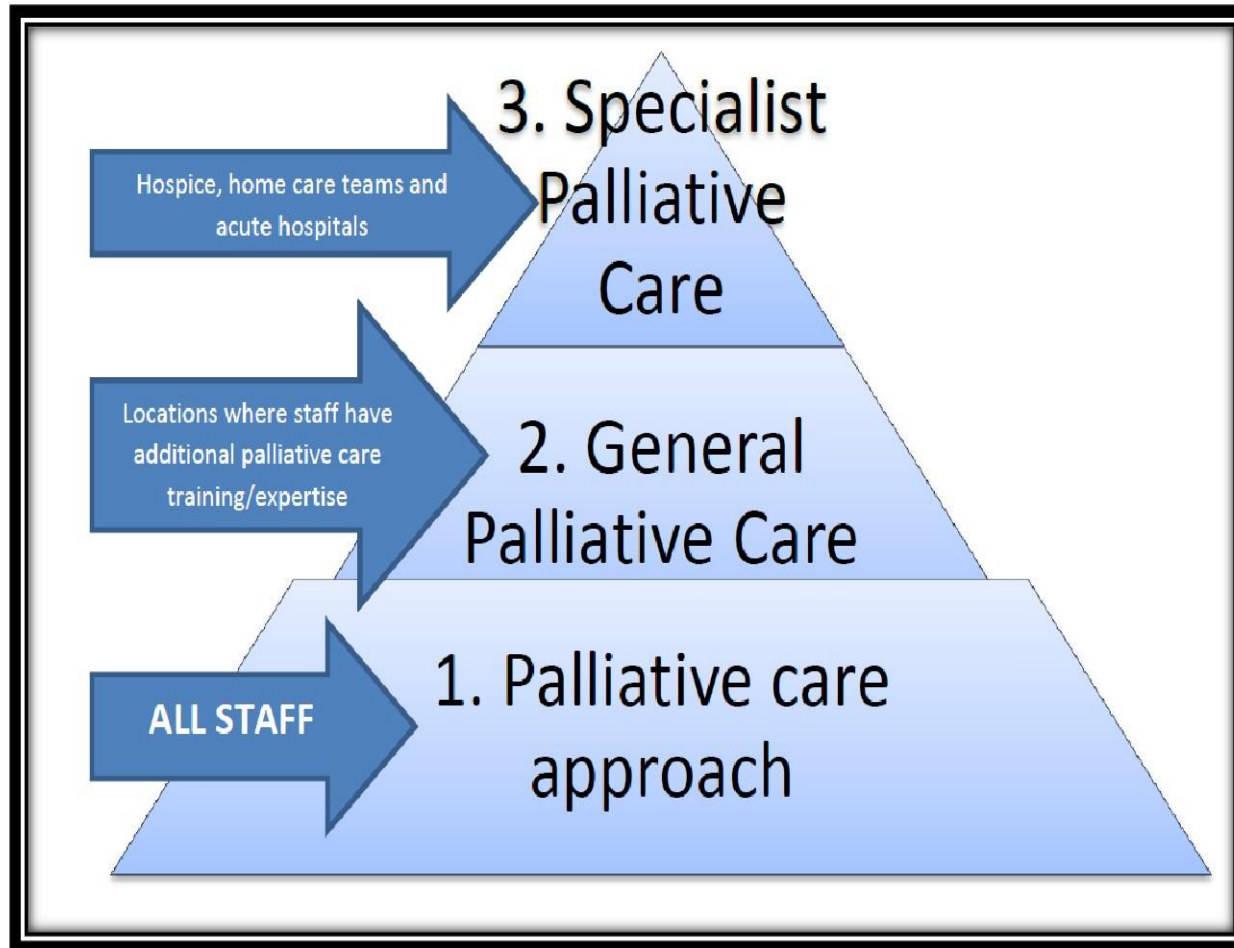
with improvements
lasting months after
initial consultation¹

DRIVES HIGH
SATISFACTION AND
POSITIVE PATIENT
EXPERIENCES

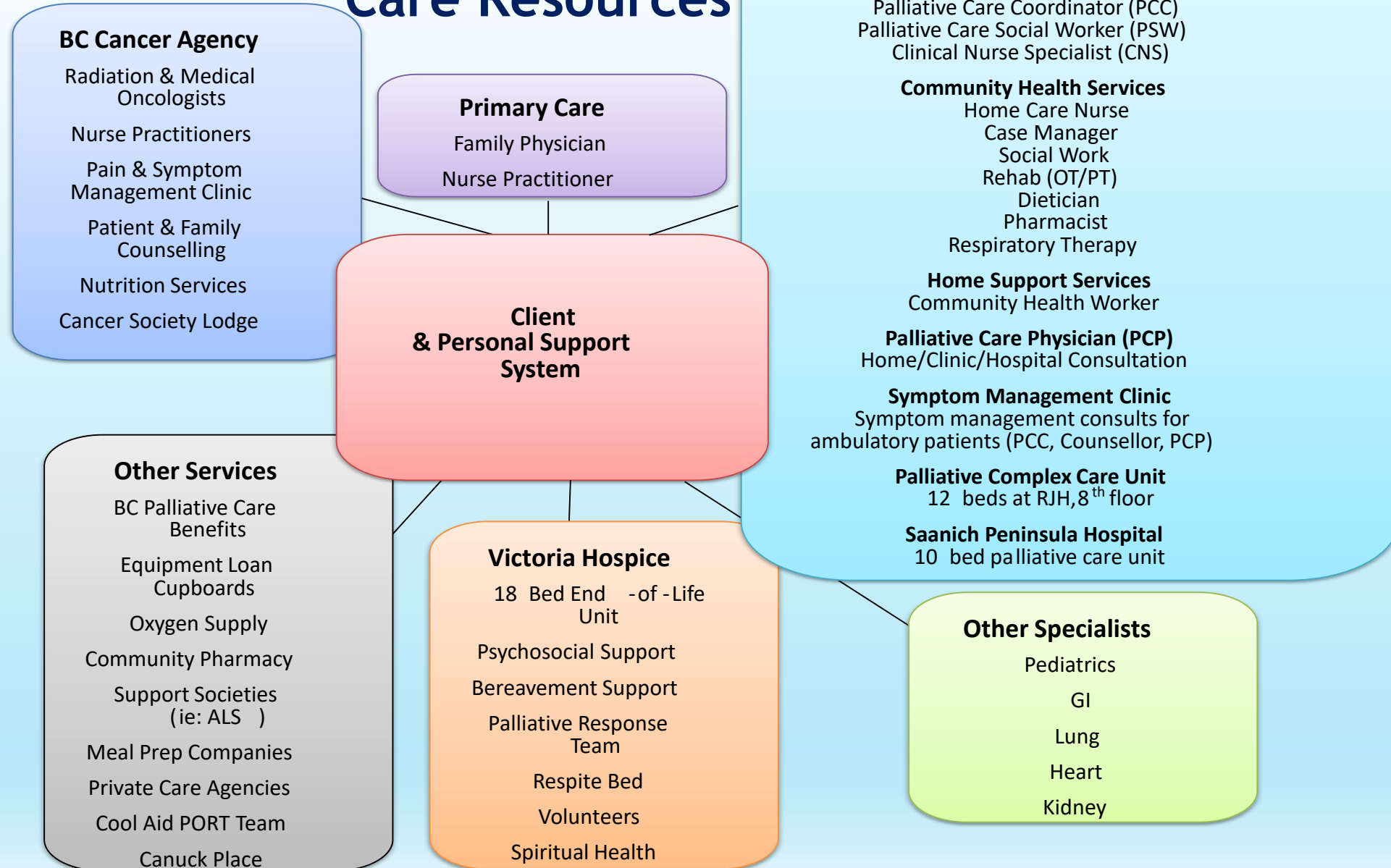
93%

of people who received
palliative care are
likely to recommend it
to others²

Center to Advance Palliative Care, 2018 Retrieved from <https://www.capc.org/tools-for-making-the-case/downloadable-tools/>



Greater Victoria Palliative Care Resources



Eligibility

- They are living with a progressive, life-threatening illness, regardless of age or prognosis.
- They live in an area of Greater Victoria served by Victoria Hospice.
- They have a family physician and the physician agrees with registration.
- Their goal of care is palliative and comfort-oriented, rather than focused on cure.
- They reside in their own home or in an Assisted Living facility.

Registration

- Registration is done through Community Health Services.

- ▶ Psychosocial and Spiritual Care
- ▶ Palliative Care Physician
- ▶ Palliative Response Team
- ▶ Community Response Coordinator
- ▶ Hospice Care Beds:
 - Goal of Care is comfort (MOST M1 or M2)
 - Prognosis up to 3 months
 - Provincial Daily rate, consent signed by client
- ▶ Bereavement Services
- ▶ Education and Research

ISLAND HEALTH PALLIATIVE AND END OF LIFE PROGRAM

- PALLIATIVE CARE COORDINATORS
- PALLIATIVE CARE PHYSICIANS CONSULTS IN ACUTE, COMMUNITY & LTC
- SOCIAL WORKERS
- PALLIATIVE SYMPTOM CLINICS
- COMMUNITY HOSPICE BEDS-ACUTE TERTIARY BEDS
- PORT TEAM
- MOST/ACP/MAID
- QUALITY IMPROVEMENT, CAPACITY BUILDING, EDUCATION

Community Health Services

- HOME CARE NURSE 8am-9pm
- REHAB: OCCUPATIONAL THERAPY/PHYSIOTHERAPY
 - LONG TERM CARE CASE MANAGERS
 - SOCIAL WORKERS
- HOSPITAL LIASIONS, COMMUNITY ACCESS,
 - DIETICIANS, SLP, RT, PHARMACIST

PORT clinical supports for inner city



New program provides palliative care to Victoria's homeless

The Palliative Outreach Resource Team employs a nurse three days a week and a physician one day a week to make house calls, wherever they may be.

RICHARD WATTS, VICTORIA TIMES COLONIST Updated: September 21, 2019

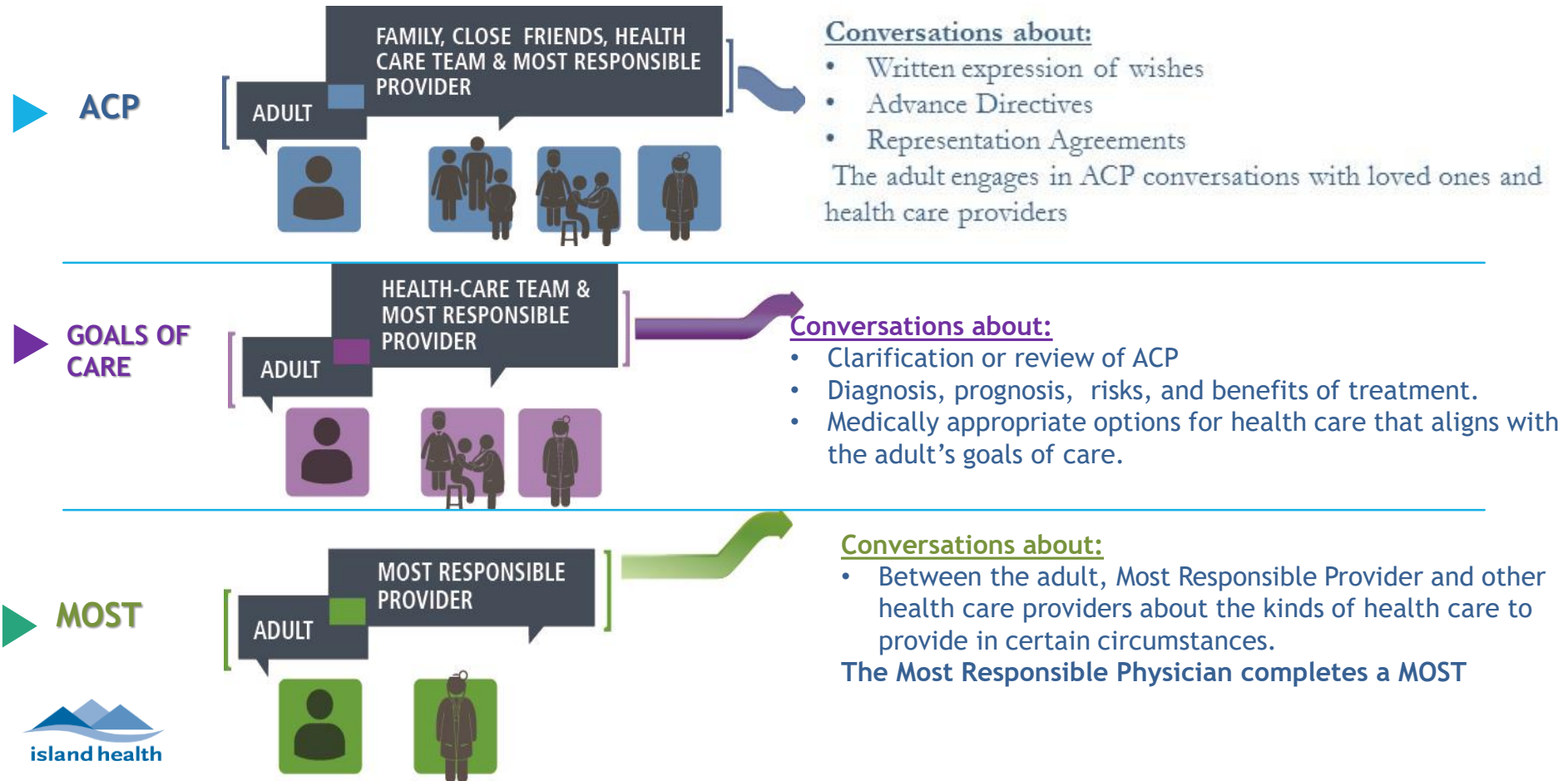


"We provide and facilitate care for people where they are at, whether that's on the street, supported housing, a motel, a car or a tent," said PORT nurse Katie Leahy. COURTESY UVIC

Structure and Process of Care

- ▶ Advance Care Planning: patient and family treatment goals are clearly documented
- ▶ Begins with a comprehensive assessment and a care plan that is consistent with a patient's values and goals
- ▶ The primary non-medical needs expressed most frequently include: a need to express emotional pain, a need to explore spiritual pain, and a need for practical financial and legal help.

Advance Care Planning: making the **MOST** of **CONVERSATIONS**



WHAT IF I WANT TO CHOOSE?

Advance Directive

Your written wishes about your health and personal care.

Includes

what kind of care you would like to receive and where
you would like to receive care.



Representation Agreement

If you want to choose someone to make your health
care decisions and be your advocate when you are
incapable,



WHY IS ACP NEEDED?

- Some adults are very clear about a treatment they want or do not want
- Decreases panic and uncertainty in a crisis
- Decreases moral distress for client, families and HCP
- Can provide a peaceful end of life experience for the patient, family, and staff.
- Individuals wishes are honored and have fewer life-sustaining procedures and lower rates of intensive care unit admissions
- Protects the autonomy of client decisions
- Promotes client/family-centered care

EARLY CONVERSATIONS ABOUT GOALS OF CARE

ARE ASSOCIATED WITH:

- Enhanced goal-concordant care
- Improved quality of life
- Higher patient satisfaction
- Better patient and family coping
- Eased burden of decision-making for families
- More and earlier hospice care
- Fewer hospitalizations
- Improved bereavement outcomes

Medical Orders for Scope of Treatment (MOST)

PART 1: RESUSCITATION STATUS and MEDICAL TREATMENTS	
Check ONE designation. CPR is provided in accordance with the MOST policy and only with C2 designation	
<input type="checkbox"/> M1	Supportive care, symptom management and comfort measures only. Allow a natural death. Transfer to higher level of care only if patient's comfort needs cannot be met in current location.
<input type="checkbox"/> M2	Medical treatments within current location of care, <u>excluding critical care interventions</u> . Transfer to higher level of care only if patient's comfort needs cannot be met in current location.
<input type="checkbox"/> M3	Medical treatments including transfer to higher level of care, <u>excluding critical care interventions</u> . Transfer to a higher level of care only if patient's medical treatment needs cannot be met in current location.
<input type="checkbox"/> C0	Critical Care Interventions, <u>excluding</u> CPR and intubation. Patient is accepting of any intervention from which they may benefit, <u>excluding</u> CPR and intubation.
<input type="checkbox"/> C1	Critical Care Interventions, <u>excluding</u> CPR but including intubation. Patient is accepting of any intervention from which they may benefit, <u>excluding</u> CPR.
<input type="checkbox"/> C2	Critical Care Interventions, <u>including</u> CPR and intubation. Patient is accepting of any intervention from which they may benefit.
PART 2: ADDITIONAL DIRECTIONS/COMMENTS related to MOST (optional)	
PART 3: SUPPORTING DOCUMENTATION (check all documents reviewed)	
<input type="checkbox"/> Previous MOST	<input type="checkbox"/> Written expression of wishes
<input type="checkbox"/> No CPR Form (BC)	<input type="checkbox"/> Advance Directive
<input type="checkbox"/> Health care provider documentation	<input type="checkbox"/> Rep 9 agreement
<input type="checkbox"/> Other	
PART 4: MOST entered following a CONVERSATION with (check at least one)	
<input type="checkbox"/> Capable Patient	<input type="checkbox"/> Personal Guardian (Committee) Name _____
<input type="checkbox"/> Representative Name _____	<input type="checkbox"/> Temporary Substitute Decision Maker Name _____
<input type="checkbox"/> Incapable Patient/Substitute Decision Maker unavailable	
PART 5: SIGNATURE OF PHYSICIAN or NURSE PRACTITIONER	
I have considered the available documents noted in Part 3 and discussed the benefits, consequences and preferences of the MOST designation with the individual(s) indicated in Part 4.	
Name (please print)	Signature
Date (yyyy/mm/dd)	Time
	Location of patient

A MOST does not replace the consent to care and treatment process.

Community PCPs, please fax form to 250-740-2687 to be entered in the EHR at eMOST activated sites.

- ▶ **OPTION 1:** Supportive Care, Symptom management, comfort care, Allow natural death.
- ▶ **OPTION 2:** Interventions to manage acute conditions outside hospital ie antibiotics, (within limits of facility/program where they reside)
- ▶ **OPTION 3:** Admit to hospital for medical or surgical treatment. No critical care transfers.
- ▶ **OPTION 4:** maximum interventions including referral to critical care but no ventilators.
- ▶ **OPTION 5:** Maximum effort including critical care, and ventilation

MOST conversations-Clarifies Goals of care

- ▶ Decisions and care based on current situation
- ▶ Dynamic, Changing, Concrete
- ▶ “CPR”/C2 is the expected standard care unless indicated otherwise
- ▶ “No CPR /M1 is essentially “Allow natural death”

Physical Aspects of Care

- ▶ Assessment should focus on relieving symptoms, improving/maintaining quality of life and functional status
 - ▶ Symptoms may include pain, shortness of breath, fatigue, nausea, constipation, etc.
 - ▶ Lack of assessment is the most common cause of unrelieved pain
- ▶ Care is delivered in a manner that is patient centered as defined by the patient's wishes

Plan for Changes

- ▶ Based on diagnosis - anticipate problems and incorporate in care planning
- ▶ Based on their goals of care, family
- ▶ Based on realities of practice environment
- ▶ Need plans & medications for potential symptoms and escalation of symptoms
- ▶ Need a clear plan - who to call for what, who is available 24/7
- ▶ Review / revise plan



A Psychosocial Perspective reminds us that...

- ▶ Illness is not simply a physical experience
- ▶ Progressive serious illness impacts and is impacted by our social, spiritual, emotional, and psychological needs and experiences.

What patients generally need/want

- ▶ The opportunity to express feelings and concerns
- ▶ The *choice* to discuss (or not) that they are dying
- ▶ Space to grieve multiple physical, psychological & spiritual losses (past, present and future)
- ▶ Use a variety of coping strategies based on previous life experiences
- ▶ Have trust in their health care providers and feel seen and respected



What families generally need

- ▶ To care and be cared for - the struggle to allow both
- ▶ Acknowledge the impact on the functioning of the family
- ▶ Express their grief or gratitude over multiple losses (past, present and future)
- ▶ Use a variety of coping strategies based on previous life experiences
- ▶ Have trust that professional care providers will be there ... that they are not alone
- ▶ Respect the patient's wishes around information sharing

BC Palliative Care Benefits

BC Palliative Care Benefits cover certain drugs, medical supplies, and equipment that are used in palliative care. These benefits are available to individuals (of any age) who have reached the end stage of a life threatening disease or illness and who wish to receive palliative care at home¹.

Who is eligible?

A British Columbia resident² who wants to receive palliative care at home can ask their physician or nurse practitioner to assess their eligibility for benefits. If they are eligible, their physician or nurse practitioner submits a registration form. Once registered, benefits continue as long as the person is in need of palliative care.

What is covered?

BC Palliative Care Benefits include two types of benefits:

- ❶ PharmaCare BC Palliative Care Drug Plan (Plan P)—Medications for palliative care.
- ❷ Local health authority—Assessment of, and coverage for, certain medical supplies and equipment³.

For more information, please read below.

❶ BC Palliative Care Drug Plan

This drug plan covers 100% of the eligible costs of palliative care prescription drugs and certain over the counter drugs listed in the Plan P formulary, including:

- **prescription medications** prescribed for pain, symptom control and improved quality of life, and
- **certain over-the-counter drugs** that are needed to supplement the prescription drugs and are considered medically necessary to support palliative care.

For the list of drugs in the formulary, visit www.gov.bc.ca/pharmacare/palliativecareformulary.pdf.

❷ Health Authority—Medical Supplies and Equipment

If you are being cared for at home, a member of your local home and community care team will assess your need for medical supplies and equipment³.

Your health authority provides the supplies/equipment at no charge. Supplies and equipment for palliative care at home may include:

- medication administration supplies such as needles and syringes
- intravenous therapy supplies
- urinary and incontinence supplies
- wound care supplies
- drug delivery pumps
- equipment such as walkers, wheelchairs, mechanical lifts, commodes, bathing aids and hospital beds

...2

COMPASSIONATE CARE BENEFITS

The 3 types of caregiving benefits

You can receive benefits during the 52 weeks following the date the person is certified by a medical doctor or nurse practitioner to be critically ill or injured or in need of end-of-life care. You can take the weeks of benefits within this timeframe either all at once or in separate periods.

The weeks of benefits can be shared by eligible caregivers, either at the same time or one after another.

Definitions

Caregiver

A caregiver is a family member or someone who is considered to be like family providing care or support to the person who is critically ill or injured or needing end-of-life care.

Family member

A family member includes immediate family as well as other relatives and individuals considered to be like family, whether or not related by marriage, common-law partnership, or any legal parent-child relationship.

Benefit name	Maximum weeks payable	Who you are providing care to
Family caregiver benefit for children	up to 35 weeks	A critically ill or injured person under 18
Family caregiver benefit for adults	up to 15 weeks	A critically ill or injured person 18 or over
Compassionate care benefits	up to 26 weeks	A person of any age who requires end-of-life care

Grief & bereavement support

- ▶ [MyGrief \(Virtual Hospice\)](#)
- ▶ [BC Bereavement Helpline](#)
- ▶ Bereavement Group for MAID (virtual)
- ▶ Vitoria Hospice (zoom counselling, workshops, support groups)

"How people die remains in the memory of those who live on"

Cicely Saunders



USEFUL INTERNET RESOURCES



www.virtualhospice.ca



www.islandhealth.ca/our-services/end-of-life-hospice-palliative-services



**VICTORIA
HOSPICE**

www.victoriahospice.org



**Family Caregivers
of British Columbia**

www.familycaregiversbc.ca





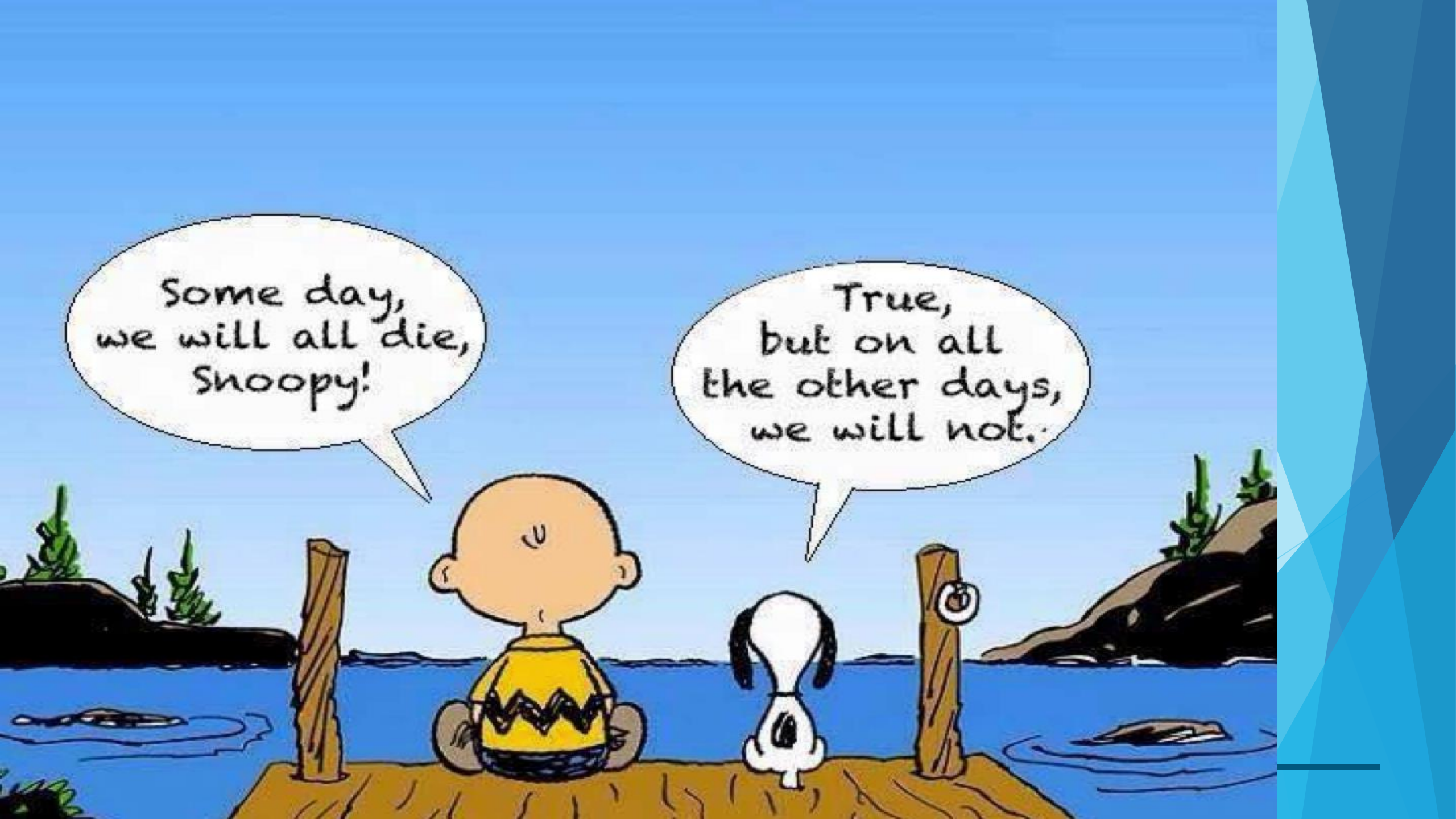


If Any Questions or Would like Clarification of Information:

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Coda

And now I know what most deeply connects us ...
and it isn't poetry, although it is poetry,
and it isn't illness, although we have that in common,
and it isn't gratitude for every moment,
even the terrifying ones, even the physical pain,
though we are halfway through
it, or even the way you describe the magnificence
of being alive, catching a glimpse ...
though it is beautiful, it is; but it is
that you're my friend out here on the far reaches
of what humans can find out about each other.
Jason Shinder



Some day,
we will all die,
Snoopy!

True,
but on all
the other days,
we will not.