

SUSTAINABLE HEALTHCARE FOR SERIOUS ILLNESS & END OF LIFE CARE

A PRACTICAL GUIDE FOR FAMILY
PHYSICIANS AND PRIMARY CARE
HEALTH TEAMS

2024
EDITION

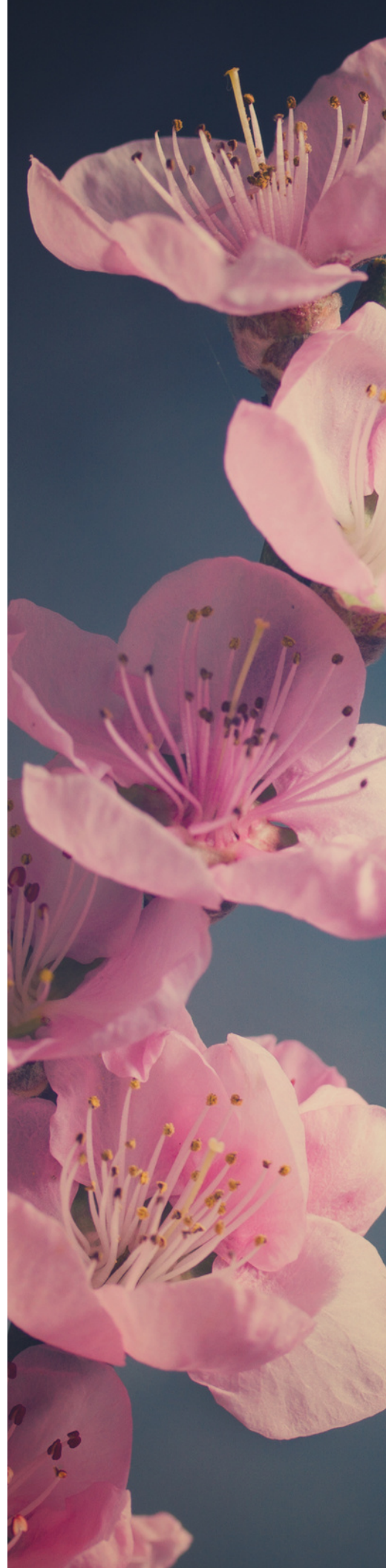
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Family Medicine



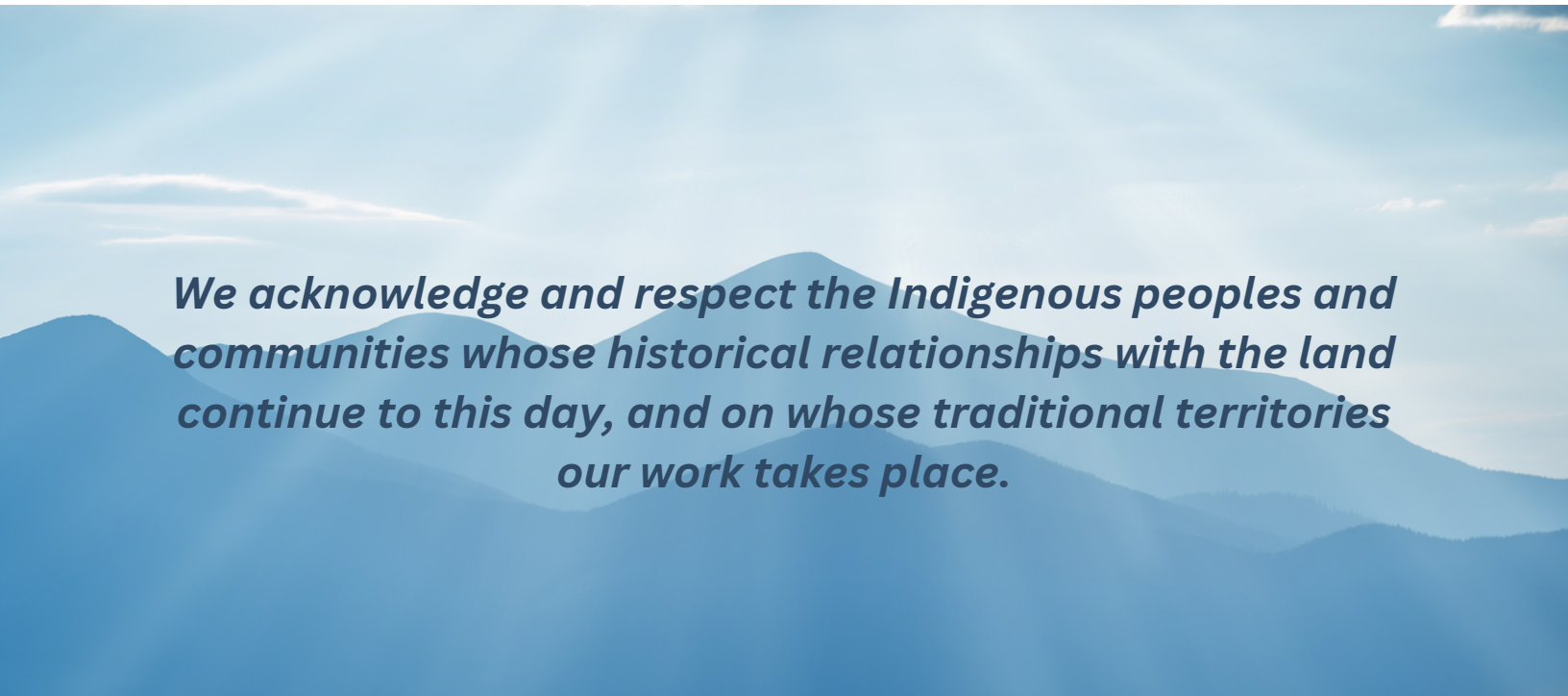
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We acknowledge and respect the Indigenous peoples and communities whose historical relationships with the land continue to this day, and on whose traditional territories our work takes place.

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1.0 INTRODUCTION

The information provided in this toolkit will assist family physicians and primary care teams in overcoming barriers when engaging in Advance Care Planning* (ACP) and in providing patient-centered care throughout a life-limiting illness trajectory, from diagnosis to End of Life (EOL). It will provide insight into the palliative approach and how environmentally sustainable practices can be integrated into patient care and healthcare delivery.

EOL is often the most medically intensive time of a person's life due to extensive hospital and long-term care stays, additional tests/lab work, and various treatments offered. Thus, it can be the costliest and highest greenhouse gas emitting time for the healthcare system (1,2). Providing patients with treatment options outside of hospital settings and aligning patient care with their treatment goals and values can lead to more sustainable healthcare delivery as well as a more peaceful death and dying process, whether in a hospital or at home.

The information and resources provided in this toolkit will ensure readers are confidently able to facilitate ACP discussions throughout their patients' lives and initiate difficult EOL conversations when their patients are given a life-changing diagnosis. Readers will also gain an understanding of what compassionate communities are and how they, patients, and caregivers can engage with them. Our intention is to impart knowledge and skills that will lead to improved patient care which inevitably results in a more sustainable health system through emission reductions and less resource usage.

The healthcare system contributes 4.4% of global emissions and with effective ACP, Family Medicine physicians are well positioned to reduce unnecessary hospitalizations (1). CO₂-equivalent emissions per day in a Canadian context (2):

- **hospital bed -- 23kg-30kg** (equivalent to driving a gas vehicle from Toronto to Barrie)
- **long-term care bed -- 3.5kg - 8.7kg**
- **home care -- less than 2kg**

Facilities with lower emissions are better suited for peaceful, non-interventional EOL care, aligning with the preferences of 87% of Canadians (3,4).



Family Physicians are often best positioned to engage with patients on ACP and EOL discussions due to their longitudinal relationships and their practice of comprehensive care across a lifespan (5).

As the topics of ACP, EOL, and the palliative approach are vast, each section of the toolkit includes practical resources to assist this audience in learning more about each topic covered.

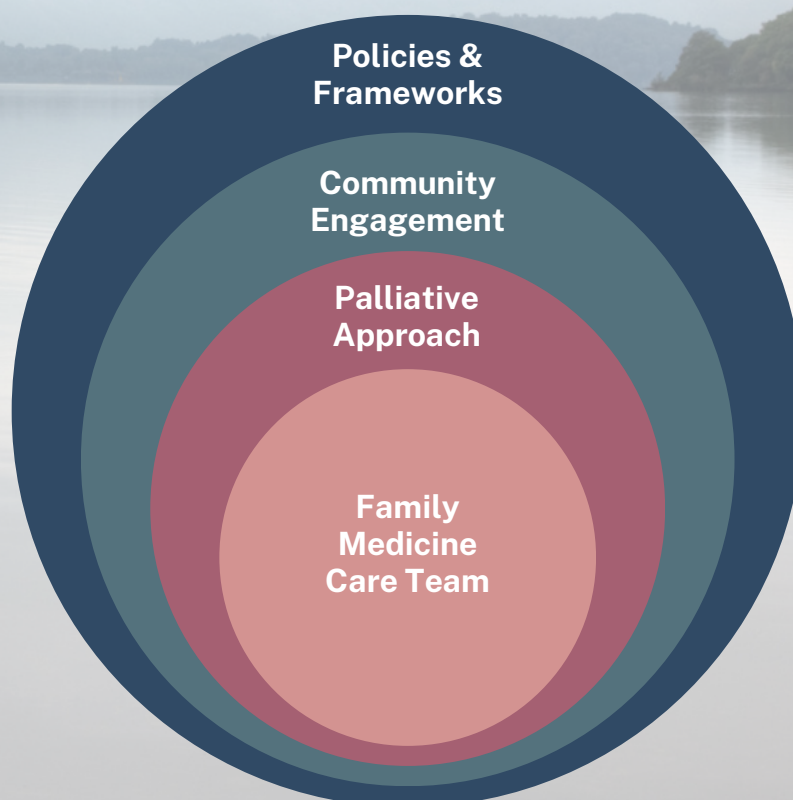
*As defined by Sudore et al (2017)., advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness (7).

2.0 APPROACH

In this toolkit, components of care are presented with an ecological approach, where each element in the system influences and interacts with the others to achieve the goal of aligning patient values with their care in a sustainable way. These elements act in a dynamic and inter-related way throughout patient care. Physicians and the patients' care teams can utilize this approach throughout their EOL journey.

It is important to note that caring for patients before, during and after the diagnosis of a life-limiting illness consists of a linear progression as well, beginning with ACP and ending with death and bereavement. Effective ACP will improve patient-centered care throughout the illness trajectory, preserve dignity, and ensure EOL decisions align with patient goals and values.

Utilizing an ecological approach in this toolkit emphasizes the interconnectedness of each stage of care during this time and highlights the complexities of patient-centered care during death and dying.



APPROACH DETAILS

Policies & Frameworks

- Advocating for more: home care options; community resources; and workplace and education system policies that further support patients, caregivers, and those grieving to ease the burden of the end of life process
- Physicians can guide patients to making informed EOL choices that also reduce health-related emission production (ie., green burials, home care rather than hospitalization)

Community Engagement

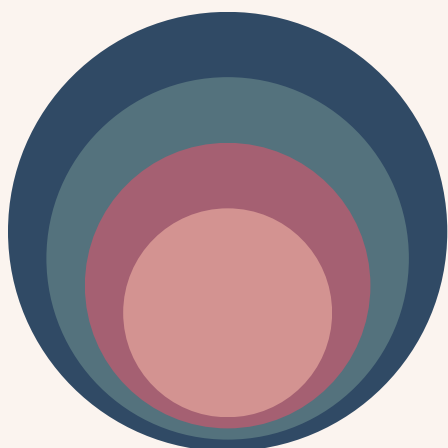
- Become aware of what community resources are available to patients
- Compassionate Communities can support healthcare teams in navigating social, emotional, and physical care for patients and their loved ones through EOL and bereavement

Palliative Approach

- Whole-person care that keeps patient's goals, values, dignity, and quality of life central to care from diagnosis to EOL
- Provide continuity of care throughout the illness to end of life and maintain the patient's advance care plans when other specialists are involved
- Treat patients and their families in a holistic manner where cultural and psychosocial supports are prioritized

Family Medicine Care Team

- Family physicians and the primary care team are well positioned to initiate Advance Care Planning conversations
- Family Physicians can effectively support patients in all aspects of care by: ensuring illness understanding; managing symptoms; planning for future care and facilitating access to additional resources



3.0 ADVANCE CARE PLANNING DISCUSSIONS



Physicians engaging in conversations with patients about their serious illness decreases patient suffering and leads to patient care that is more in line with the patient's preferences (15). ACP discussions are also associated with reduced deaths in hospitals (16). Since hospital care produces more GHG emissions and resources consumption compared to homecare, engaging in ACP can be an effective means for family physicians to reduce the carbon footprint of healthcare, while aligning care to patient's wishes (2).

ACP discussions with a healthcare provider can start or be re-visited when the condition interferes with the patient's quality of life. Some examples of how/when to initiate ACP discussion are:

- Asking yourself, "Would I be surprised if this patient were to die within the next 12 months?"(17)
- Identify patients that are in a specific disease population or age group (e.g., 65+), this can be done via EMR prompt, letters, or handouts to patients about ACP (18)
- Patient brings up a recent loss or mentions fear of dying due to recent health scare (19)



Use of validated tools (such as The Serious Illness Conversation Guide) can provide a successful format for starting ACP conversations. Family physicians can also connect patients with public resources and assist in answering questions around a patient's substitute decision maker (SDM), selection of a Power of Attorney (POA) for health and property, as well as clarifying what these roles do and do not entail (21, 22).

ACP Conversation Starters:

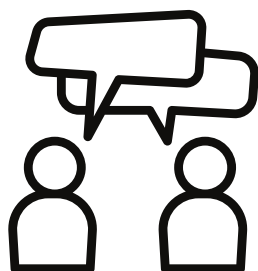
- “Have you noticed a change in yourself recently and what do you think is happening?”(19)
- “Can we step back and look at the big picture?” (20)



Resource Links

- [ACP communication Tools](#)
- [Power of Attorney overview: Examples of ACP/EOL forms to be provided to patients](#)
- [Substitute Decision Making overview](#)
- [Gold Standards Framework Prognostic Indicator Guidance](#)
- [Edmonton Symptom Assessment System Tool \(common symptoms\)](#)
- [Advanced Directives](#)

4.0 ENHANCING AWARENESS OF RESOURCES AND TOOLS FOR FAMILY PHYSICIANS



There are many valuable tools and models of care available to family physicians and the patient's care teams that provide support in carrying out palliative care and engaging in ACP (8). Family physicians becoming aware of and offering connections with community resources, services, and programs related to grief and dying can ease a patient's journey.

Physicians learning from one another's experiences in ACP and EOL patient care teams can improve mortality awareness within the field and can lead to the integration of ACP conversations earlier in people's lives (9). Community or healthcare worker led educational content, with a focus on conversation, can help family physicians improve patient knowledge and motivation to start ACP (10).



Resource Links

Canadian Resources

- [Advance Care Planning Ontario](#)
- [Resources that honour culture, spirituality, and traditions](#)
- [Care Connection programming](#)

International Resources

- “[Respecting Choices](#)”, a guide for person-centered decision helps providers ensure individual preferences and decisions for healthcare are known and honored
- “[The Serious Illness Care Program](#)”, a system-level care delivery model created by a team of palliative care experts with the goal of having more, better, and earlier ACP

Cultural, religious, and community practices and traditions also play a part in how patients want to be engaged with and how they will conduct ACP and EOL preparations (11). Being aware of various cultural practices and connecting patients to supportive programs that correlate with their belief systems is essential in providing whole-person care.

5.0 FAMILY PHYSICIAN SUPPORT OF PATIENTS FROM DIAGNOSIS TO END-OF-LIFE CARE

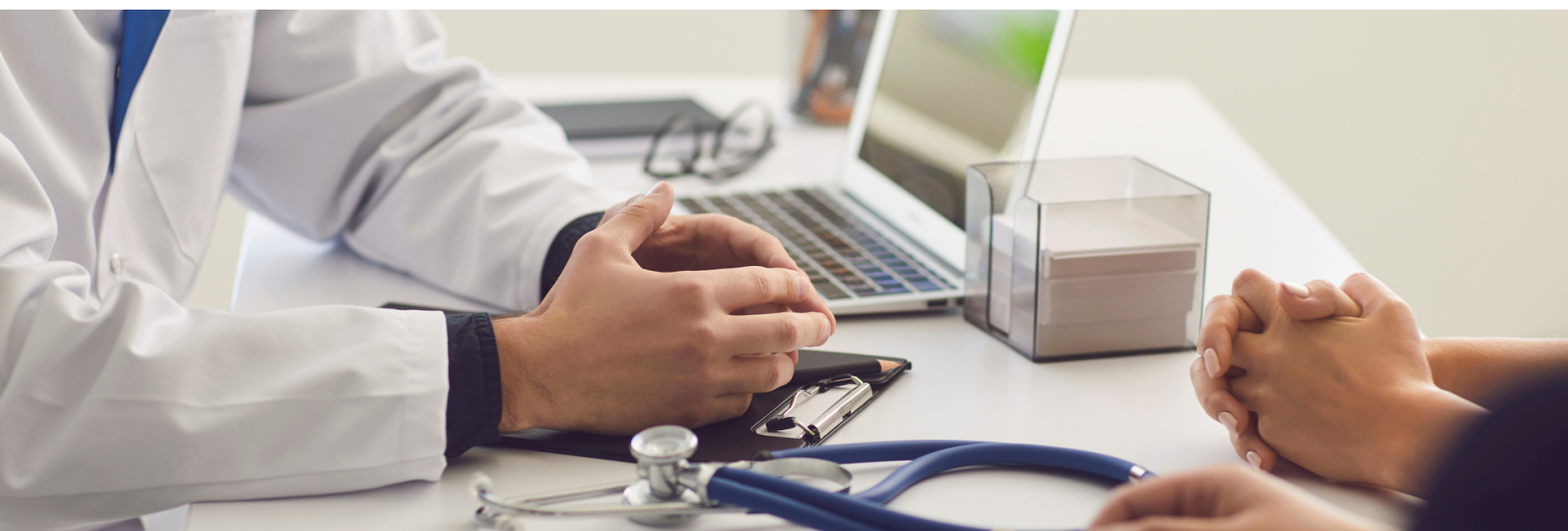


Family Physicians are well positioned to help patients in understanding their disease/diagnosis and associated symptoms. Due to their long-term relationships with patients, family physicians are also in the position to start ACP discussions while patients are healthy or prior to escalation of serious illness (5). Further, trusting relationships between clinicians, patients, and family members are associated with better experiences throughout the illness journey by family members of the dying patient (12).



Resource Links

- [Serious Illness Conversation Guide and supporting resources](#)
- Examples of ACP/EOL forms to be provided to patients:
 - [DNR-C P Order Form](#)
 - [Letter of Understanding – Pronouncement and Certification of Death](#)
 - [Medical Certificate of Death](#) (for a version that can be submitted electronically via e-mail mcod.support@ontario.ca)
- [End of life options](#)
- [MAID facts](#)





Actions

Some items that Family Physicians can lead during ACP and EOL are:



- Being the first line of medical expertise, providing compassionate clarification around diagnosis, specific symptom management and treatment options



- Ensure patient's values and wishes are known to to substitute decision maker and care team during EOL



- Being available during illness exacerbations – home visits, emergency admission to hospital
- Supporting the emotional and physical effects of diagnosis for patients and their families



- Address caregiver burden with patient's circle of care and organizing respite care if needed



- Coordinate care including collating information from specialists, evaluating needs for external services, and liaising with additional specialists (e.g. Social workers, physio, occupational therapy, etc.) (5,13,14)

6.0 PALLIATIVE APPROACH TO CARE

In patients with a life-limiting illness, a palliative approach keeps the patient's values, goals, and dignity at the core of care. Sawatzky and colleagues identified three main ideas outlining a palliative approach (5):

- **Focusing Upstream:** Paying attention to the needs of people and their families who are dealing with life-limiting conditions, even before they become severe.
- **Adaptation:** Adaptation of palliative care knowledge and expertise to the illness trajectories of people with chronic life-limiting conditions
- **Operationalizing Palliative Care:** Making sure that the palliative approach is seamlessly incorporated into different healthcare systems and models, even if they aren't specifically focused on palliative care.

This approach does not necessarily require specialized palliative care doctors or extra resources beyond what is already available in family practice. In fact many physicians engaging in the palliative approach are unable to define when general treatment transitions to palliative care (24). What we do know is that when palliative care or the palliative approach is implemented too late, is it associated with increased use of higher acuity services, and an increased environmental and financial strain on the health system (2, 24).



Resource Links

- [Podcast: The Waiting Room Revolution](#)
- [Ontario Palliative Care Network's \(OPCN\) Tools to Support Earlier Identification in Palliative Care](#)
- [Better Early than Late - video on the importance of early palliative care](#)
- [The Way Forward – palliative approach to care tools and resources](#)

7.0 LATE-STAGE PALLIATIVE CARE



For family physicians, it is important to work with the other specialists involved in the patient's care, when possible, and integrate the patient's ACP into their treatment. Patients that have engaged in ACP have decreased ICU admissions and, if they are admitted to hospital, their length of stay is shorter compared to those who have not (25).



It is often necessary to broaden care to a patient's family and friends to address the psychosocial and spiritual issues that are inherent to the dying process (26). In addition, connection with Compassionate Communities can be a valuable support for patients and caregivers at this time.



During the final days of someone's life, a specialized care team can be more involved for complex situations. The role of a family physician remains central for continuity of care, maintaining communication with family members, and providing decision support (27). In some cases constraints such as resources and geography may limit the family physician from being physically present, but if the patient has previously engaged in ACP, the EOL care team will have the information necessary to align care with the patient's goals and values (6).



For patients that wish to stay in their homes during EOL care, new innovations such as personal health budgets that allow the health team to purchase extra resources at EOL to keep patients supported at home, can ensure patients achieve their preferred place of death (28). As new innovations emerge, family physicians can help patients choose the right options for them and their families.



Resource Links

- [FICA Tool \(spiritual assessment\)](#)
- [The Dignity Model \(psychosocial assessment\)](#)
- [Palliative performance scale](#)
- [Family caregiver financial support options](#)

8.0 UNDERSTANDING AND ENGAGING WITH COMPASSIONATE COMMUNITIES

The intention of compassionate communities is to normalize EOL support, bereavement, and grief. Compassionate Communities can improve quality of life for people with a life-limiting illness and their families by encouraging people to advocate, aid, and offer practical support within their community. This approach focuses on the patient as a whole person, addressing physical, mental, social, and spiritual needs. (29, 30).



Actions

These communities can be created based on a geographical location, a group of people with a united purpose, or even an online community (29,30). Within a compassionate community, workshops or community events are typically facilitated by volunteers to enhance healthcare resources. A few examples are:

- Establish a walking group with some members trained to support the bereavement process
- Student placements in hospice care settings
- Hosting games and information sessions about ACP at community centers
- Workshops and peer support groups to help cope with grief; specific materials can be created to support children and youth





Compassionate communities connect physicians, patients and their families with a network of treatment resources and social supports that already exist in their communities, such as social groups, religious organizations, and befriending services (33). An added benefit of this is creating a culture where ACP discussions become easier to facilitate and patients are less hesitant to bring these topics up to their care teams (31,32).

A practical first step for primary care providers to create and bolster compassionate communities could be posting information on social media or in waiting rooms (e.g. Brochures) on community supports outside of the healthcare system for people affected by death, dying, loss, grief or bereavement (34).



Resource Links

- [Pallium Compassionate Communities Toolkit](#)
- [Pallium Care Connection Programs](#)
- [Compassionate Communities Community of Practice](#)
- [Home and Community Care Support Services](#)
- [Examples of Compassionate Communities in Canada](#)
- Books that provide additional insight into palliative care and compassionate communities:
 - Hope for the Best, Plan for the Rest: 7 Keys for Navigating a Life-Changing Diagnosis. By: Dr. Samantha Winemaker and Dr. Hsien Seow
 - Being Mortal. By: Atul Gawande

9.0 HOME CARE



Dying at home and limiting their hospital stays is a goal of most patients. Dedicated home care teams can provide care in line with patient wishes. Important components of homecare include: an integrated team, proactive care, management of physical symptoms, caring and compassionate providers, and holistic care (35). Primary care teams can act as informal ‘managers’ of their patient’s home care through facilitating the medical, social, and comfort components of care.



Future Considerations: Small Care Homes

Rather than the typical long-term care facility, a Small Care Home is designed to mimic a family home setting within a neighborhood/community. They house less people than a traditional facility, with private rooms and same degree of care as in a typical medical setting.

- On average, 63% of Canadians are hospitalized in their final year of life, and these patients spend an average of 33 days in hospital over the course of 2.1 admissions (2)
- Small care homes house up to 12 adults and are easily integrated into community settings. They consist of all the amenities of a nursing home but are designed to look and feel like a regular home. Due to their size, there is potential for GHG emission reductions as well (3)

Home care is also a more cost-effective approach for the healthcare system (24). Every community has different resources and care options; thus, homecare should be tailored to fit the unique needs of the patient and community they are a part of (35). Having a strong understanding of what is available, how to access it, and how to advocate for more services should be a goal of primary care teams (35).

Those who have a dedicated homecare palliative team were more likely to die at home, have fewer hospitalizations, and spend fewer days in hospital in the last 2 months of life (36). This reduction in hospital stays greatly reduces the greenhouse gas emissions associated with EOL care. Each homecare patient could save as much as 95% GHG emissions associated with their care per day by staying out of hospital facilities (2).

- Use of technologies in long term care homes and retirement homes allows patients to engage with their care team virtually. This:
 - Reduces the spread of disease within a vulnerable population
 - Eases access to specialists
 - Increases staff capacity
 - Limits driving for staff and patients, reducing associated GHG emissions (16% of Canadian household carbon emissions are attributed to personal transportation) (37)
- To reduce the financial burden of family members caregivers, new research and policies are emerging that would position family caregivers as “Healthcare workers” and employees of home care agencies. As employees they are entitled to hourly pay, sick time, regulated hours, vacation pay, etc., reducing the financial and emotional toll of caregiving (38).

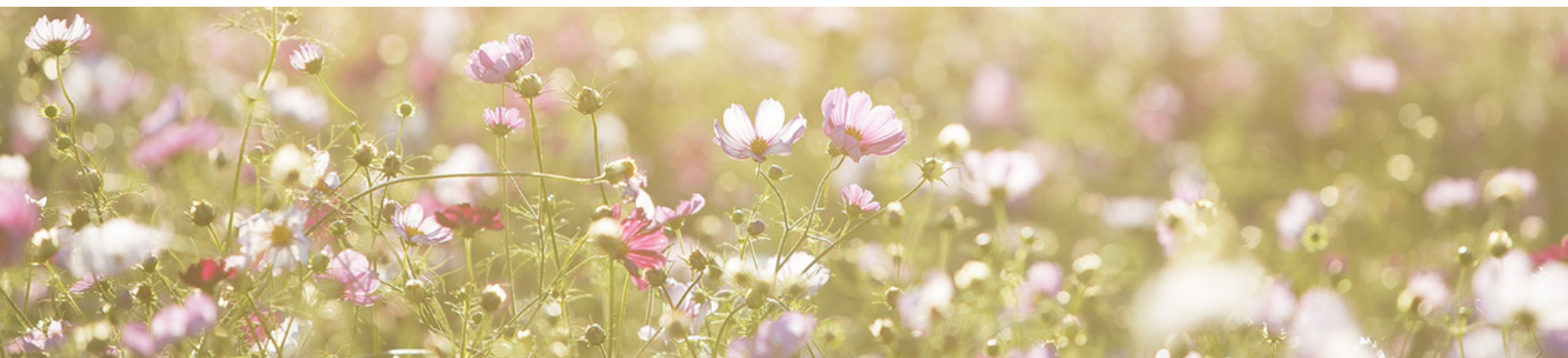


Resource Links

- [Canadian homecare association](#)
- [Canadian Virtual Hospice](#) is a free online resource for all things palliative care, including psychosocial and spiritual resources (for clinicians, caregivers and families)

10.0 ENVIRONMENTALLY CONSCIOUS BURIALS

During the ACP and EOL discussion, family physicians can inform patients on different burial options. Traditional cemeteries emit toxic chemicals to the environment through casket materials, embalming, and lawn treatment with pesticides. Cremations use around 28 gallons of fuel and release 245kg - 400kg of CO₂ per single cremation. The fumes often include vaporized mercury and other gases from tooth-fillings and prosthetics (39, 40).



Green burials, on the other hand, involve a combination of body preparations and burial practices that allow the body to decompose naturally and have the least negative environmental impact. Delivery of a green burial differs depending on the request of the deceased and their families, but they do involve a standard set of practices: no embalming, direct earth burial, ecological restoration and conservation, communal memorialization, and optimized land use (41).

Several maps and resources are available online to determine where green burial sites are located and how to include them in burial planning.



Resource Links

- [Starting the conversation on sustainable EOL](#)
- [Green burial sites in Canada](#)
- [Green burial planning guide](#)
- Book: The green burial guidebook: Everything you need to plan an affordable, environmentally friendly burial. By: E. Fournier (2018)

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The original project was conceptualized by Dr. Myles Sergeant.

All authors contributed to background research, content discussions, and reaching consensus on presented information.

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All authors agree on the content presented in the final product.

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